



**New York State
Developmental Disabilities
Planning Council**

David A. Paterson
Governor

George E. Fertal, Sr.
Chairperson

Rose Marie Toscano
Vice-Chairperson

Sheila M. Carey
Executive Director

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Great Seal of the State of New York

**New York State
Developmental Disabilities
Planning Council**

***Annual
Report
2008***

10-01-07 / 09-30-08

**The New York State
Developmental Disabilities Planning Council (DDPC)**
is a federally funded state agency working under the direction of
Governor David A. Paterson.

The **DDPC** is responsible for developing new ways to improve the delivery of supports and services to New Yorkers with developmental disabilities and their families. The Council focuses on increasing the opportunities for consumers to become more involved in the community, secure education, employment and housing.

The **DDPC** affects positive systems change through grant programs that fund such activities as:

- *Demonstration programs*
- *Training for all families and staff*
- *Outreach to un-served / underserved populations*
 - *Support to communities*
- *Interagency collaboration and coordination*
 - *Systems design and redesign*

To a large extent, **DDPC** programs are developed in direct response to the concerns and ideas voiced by consumers, families, services providers, policymakers and other professionals.

George E. Fertal, Sr.

Chairperson

Rose Marie Toscano

Vice-Chairperson

Aldea LaParr

Consumer Caucus Chairperson

Sheila M. Carey

Executive Director

New York State DDPC Members

George E. Fertal, Sr., *Chairperson*

Consumer Member

Rose Marie Toscano, *Vice-Chairperson*

Consumer Member

Michelle Appleby

Consumer Member

Ansley Bacon, Ph.D.

Director, University Centers for Excellence Member

Hon. Michael J. Burgess

Director, NYS Office for the Aging

Hon. Dr. Richard F. Daines, M.D.

Commissioner, NYS Department of Health

Patricia Edelstein

Consumer Member

Virginia M. Ellis

Consumer Member

Hon. Brian S. Fischer

Commissioner, NYS Department of Corrections

Janice A. Fitzgerald

Non-Governmental Agency Member

Tamelia Laquana Fritz

Consumer Member

Hon. Astrid C. Glynn

Commissioner, NYS Department of Transportation

Shirley Goddard

Consumer Member

Hon. David A. Hansell

*Commissioner, NYS Office of Temporary
and Disability Assistance*

Kevin Kennedy

Consumer Member

Aldea LaParr

Consumer Member

Barbara Levitz

Consumer Member

Lawrence Lieberman

Consumer Member

Continued...

New York State DDPC Members...continued

Jane G. Lynch	<i>Chief Operating Officer, NYS Commission on Quality of Care and Advocacy for Persons with Disabilities</i>
Robert W. Marion, M.D.	<i>Director, University Centers for Excellence Member</i>
Reverend Dennis Meyer	<i>Consumer Member</i>
Hon. Richard P. Mills	<i>Commissioner, NYS Education Department</i>
Wendy P. Orzel	<i>Consumer Member</i>
Rain Rippel	<i>Consumer Member</i>
Hon. Diana Jones Ritter	<i>Commissioner, NYS Office of Mental Retardation and Developmental Disabilities</i>
Anne L. Scherff	<i>Consumer Member</i>
Dawn Schessl	<i>Consumer Member</i>
Beatrice Schmidt	<i>Consumer Member</i>
Stephen B. Sulkes, M.D.	<i>Director, University Centers for Excellence Member</i>
Hon. Deborah VanAmerongen	<i>Commissioner, NYS Division of Housing and Community Renewal</i>
Patricia Washburn	<i>Consumer Member</i>

A message from the...

Chairperson and Executive Director

...of the

New York State Developmental Disabilities Planning Council

On behalf of the membership and staff of the **New York State Developmental Disabilities Planning Council (DDPC)**, we are pleased to present to you the DDPC Annual Report for federal fiscal year (FFY) 2008.

2008 marks the second year of our *2007-2011 Five-Year State Plan*. The **DDPC**, in conjunction with our grantees, have vigorously addressed achieving the objectives that comprise the *2007-2011 Five-Year State Plan*.

We are proud of our many accomplishments. **We are proud that the DDPC is recognized as a national leader amongst our counterparts.** The 2008 Annual Report gives you the opportunity to review those accomplishments.

Each year, the **DDPC** moves forward in achieving the goals that our *2007-2011 State Plan* has put forth. Each of these goals is constantly reviewed by our membership and staff and adjusted to reflect the changing environment of New York State and the nation. Most importantly, the resulting goals are reflective of the changing needs and requirements of New Yorkers with developmental disabilities and their families.

Included in this 2008 Annual Report is a review of the DDPC Tracking Portfolios that which monitors progress toward meeting our goals and objectives. We would also like to share with you several exceptional accomplishments of the DDPC for 2008 that reflect our grantee efforts in bringing these programs to fruition.

Continued...

A message from the...

Chairperson and Executive Director *(Continued)*

The year 2008 marks the 37th anniversary of State Councils on Developmental Disabilities and the 1970 reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). Originally authorized in 1963, the DD Act was reauthorized in 1970 and every several years until its most recent reauthorization which was enacted on October 30, 2000. The next Congressional reauthorization is scheduled for the 111th Congress. The DD Act has always focused on the needs of an estimated 4 million individuals with developmental disabilities living in the United States and its territories.

For New Yorkers with developmental disabilities and all Americans with developmental disabilities the DD Act has helped to convert an institutional service system to a community based service system with more work yet to be done as self-directed services become more prominent. Collectively, we must channel our efforts towards the successful reauthorization and we will be asking you to assist in that effort.

As we look ahead to 2009 we all face a global economic crisis that will affect each of us in many ways. We have begun an extensive review of all our programs to ensure that all New Yorkers with developmental disabilities and their families continue to be recognized for all that they have done and continue to do and not be penalized by the economic environment.

We welcome your input, your suggestions, and your assistance.

Sincerely yours,

The image shows two handwritten signatures in blue ink. On the left is the signature of George E. Fertal, Sr., which is written in a cursive style. On the right is the signature of Sheila M. Carey, also in a cursive style.

George E. Fertal, Sr.
Chairperson

Sheila M. Carey
Executive Director

Facts & Figures

Concerning...

2008 New York State DDPC Funded Programs

Creating a World of Change

...for

New Yorkers

**with developmental disabilities
and their families.**

With \$4,237,748 the DDPC did the following...

- **14,404...*Individuals / Families Served***
- **202...*Programs / Policies Created***
- **\$15,654,030...*Was leveraged***
- **\$2,529,176...*Grantee Matching Funds***
- **41,207...*People Involved in DDPC Funded Training***
- **4,538...*People Active in Advocacy & Change Efforts****
- **549,040...*Members of the General Public Reached***
- **256...*Products Developed***
- **14,198...*Products Distributed to Policymakers***
- **115,077...*Products Distributed***

**People engaged in a variety of activities with the intent to change the way services and supports are planned, provided and funded.*

**New York State
Developmental Disabilities Planning Council
23rd Annual Achievement Awards**

Each year since 1985, the New York State Developmental Disabilities Planning Council (DDPC) has conducted its annual Achievement Awards program to promote public awareness of the capabilities, value, and potential of persons with developmental disabilities.

The DDPC Achievement Awards program recognizes individuals and organizations in the community who have provided support and assistance to New Yorkers with developmental disabilities.

2008 Recipients

- **Erwin Schmidtkunz**
Exceptional Personal Growth
- **Susan Barrett**
Substantial Influence on the Lives of Others
- **Ruth Ridgway**
Volunteer of the Year
- **Bethany Village**
Employer of the Year
- **Pauline Cotter**
Direct Support Employee of the Year
- **Nicholas Loretta**
Direct Support Employee of the Year
- **Margaret Mikol**
Administrative Employee of the Year
- **Ann Hardiman**
Community Leader of the Year
- **Korey McCoy / Plaza Fitness @ Stuyvesant Plaza**
Recreation Provider of the Year
- **Jowonio School / Jane Dagenais**
Everyday Life / Images of Inclusion
- **Mike Attwell**
Lifetime Achievement / One Who Has Made a Difference
- **Karen Medina**
Certificate of Recognition

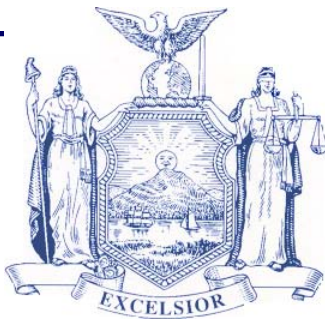
DDPC Grantees in 2008

- **Access to Independence**
- **Adirondack ARC**
- **Advocacy Center**
- **American College of Obstetricians and Gynecologists / District II**
- **ARISE Child & Family Services**
- **Best Buddies New York, Inc.**
- **Brain Injury Association of New York State**
- **Boys and Girls Clubs of Northtowns**
- **Center for Disability Services**
- **Consortium on Innovative Practices**
- **Cornell University**
- **DD Alliance of Western New York**
- **Eastern Suffolk BOCES**
- **Elmhurst Hospital Center**
- **Families Together in New York State**
- **FEGS**
- **Franklin County Public Transportation**
- **Genesee ARC**
- **Health Research, Inc. (HRI) / Council on Graduate Medical Education**
- **Hospice and Palliative Care Association**
- **Institute for Urban Family Health, Inc.**
- **Job Path**
- **Life's WORC**
- **Maimonides Medical Center**
- **Montefiore Medical Center**
- **New Alternatives for Children**
- **New York City Department of Health & Mental Hygiene**

DDPC Grantees 2008

(continued...)

- **New York Medical College Department of Pediatrics**
- **New York Presbyterian Hospital**
- **NYS Association of Community and Residential Agencies**
- **NYS Office of Mental Retardation and Developmental Disabilities**
- **New York State Citizens' Coalition for Children**
- **North Country Center for Independence**
- **Oswego County Opportunities**
- **Resource Center Independent Living**
- **Rockland Independent Living Center**
- **Self-Advocacy Association of New York State**
- **South Nassau Communities Hospital**
- **St. Mary's Hospital for Children**
- **Sunmount Developmental Disabilities Service Office**
- **State University of New York Cortland**
- **State University of New York Upstate Medical University**
- **Support Center for Nonprofit Management**
- **Town of Islip Youth Bureau**
- **United Cerebral Palsy of New York City, Inc.**
- **Visiting Nurse Regional Health Care System, Inc.**
- **Westchester Disabled On the Move**
- **Westchester Institute for Human Development**
- **Western New York ILP**
- **Wildwood Programs**



Great Seal of the State of New York

**New York State
Developmental Disabilities
Planning Council**

Mission Statement

The New York State Developmental Disabilities Planning Council (DDPC) in collaboration with individuals with developmental disabilities, their families, caregivers and policymakers provides capacity building by promoting policies, plans and best practices that:

- **Affirm the dignity, value, respect, contribution and worth of all New Yorkers with developmental disabilities.**
- **Support full participation of people with disabilities in society.**
 - **Uphold equality and self-determination for all.**
- **Promote access to research and information needed for informed decision making.**
- **Convene individuals with disabilities, family members, service providers and others to learn from each other to promote promising system changes.**

A Few Of Our Success Stories In 2008

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• Best Buddies New York

Best Buddies New York (BBNY) is a non-profit organization dedicated to enhancing the lives of people with intellectual disabilities by providing opportunities for one-to-one friendships. BBNY has offices in Long Island, Manhattan, and Albany, and the programs at middle schools, high schools, and colleges statewide currently impact the lives of nearly 10,000 residents throughout the state of New York.

BBNY's high school and middle school-based programs match students with intellectual disabilities ("Buddies") in one-to-one friendships with their non-disabled peers ("Peer Buddies"). A staff member, the Program Manager, recruits and guides student leaders in running successful chapters. Student leaders recruit Buddies and Peer Buddies to be matched in friendships ("Buddy Pairs"), taking common interests and transportation needs into account so that friends are compatible. Each chapter also enlists the help of a Special Education Advisor and a Faculty Advisor - teachers who volunteer to provide guidance to chapter officers and who act as liaisons between school administration and chapter members.

Through the BBNY Middle School Socialization Project, which was funded by the New York State DDPC, BBNY has been able to open 27 new chapters at middle schools throughout the state since 2006. These chapters have directly engaged over 1,200 youth with and without developmental disabilities in long-term, mutually enriching friendships, and have changed school community dynamics to a significant extent. Nine additional chapters are under development and slated to be opened by the fall of 2009. The success of this project is demonstrated by the following story.

Amy, a student with developmental disabilities at Sequoya Middle School, does not communicate verbally, and sometimes gets very agitated. During a recent chapter meeting, the BBNY Program Manager noticed that Amy was getting upset. Then she saw Amy's Peer Buddy, Jessica, reach over and take Amy's hand and begin to comfort her. Amy, who usually only looks up at the ceiling and lights, made eye contact with Jessica and was able to calm down. This was a beautiful display of friendship between two middle school aged peers.

**Two "Best Buddies"
share a special moment.**



• **Transportation and Employment**

The DDPC Transportation and Employment initiative was designed to improve access to transportation, increase the knowledge and awareness of transportation options, and provide the supports and coordination between transportation providers and community based organizations. A major project goal was to link people's access to employers, the community, local One-Stop Employment Centers and other essential services and supports.

• ***Franklin County Public Transportation***

To open up job opportunities for those without other means of transportation, Franklin County Public Transportation created the new Adirondack Route in June 2008. The new route carries passengers to jobs and other destinations between Malone, Lake Placid, Paul Smith College and Tupper Lake. Ridership has increased from 6,000 to 12,000 riders, and \$47,000 in outside funding has been secured to ensure the continued success of this program.

• ***Oswego County Opportunities (OCO)***

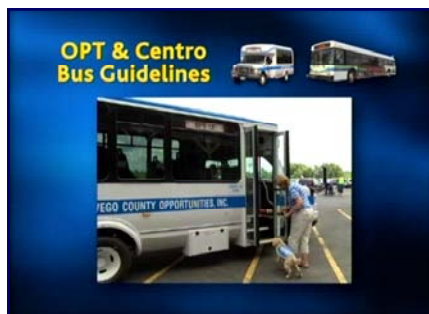
Recognizing that accessible public transportation is key to quality of life and inclusion within society, Oswego County Opportunities has aimed to improve knowledge and perception of public transportation to persons with disabilities. In an effort to make access to employment "barrier free," OCO has been working to develop and monitor a travel training program to establish best practice in that field. OCO will soon be offering free travel training for those who wish to train others on the use of the public transportation system. All of this information will be accessible on their upcoming web site, *Happy Travels*.

• ***Developmental Disability Alliance of Western NY***

The Developmental Disability Alliance of Western New York (DDAWNY) has established a central dispatching system for use by the 30+ agency alliance members. The intent is to avoid transportation duplication, cut travel costs, reduce the time of commutes and improve user satisfaction with transportation services and supports. DDAWNY, in collaboration with the Center for Transportation Excellence (CTENY), has formed a Driver Sensitivity Program, which educates drivers in best customer service practices and how to effectively provide assistance to riders in need or distress. DDAWNY and CTENY are also working together to develop strategies to increase and simplify opportunities for small business transportation providers to expand their services.



*Franklin County
Public Transportation*



*Oswego County
Opportunities*



*Developmental Disability
Alliance of Western NY*

• Spirit Project

To build community awareness around spiritual inclusion, the Spirit Project produced posters to be placed around the community. This is one way to share messages about people with disabilities being included in their community through faith-based involvement in faith communities. To make sure that the messages represented the Central New York DSO community where the posters would be distributed, an Exceptional Artworks contest was held. Artists with disabilities submitted 27 separate art entries in response to the request for designs that depicted the theme “People Connected through Faith.”



David Burns, photographer, and, Spirit Project Director Marcey Dolgoff Alter, holding David's angel photo.

Three designs were chosen for poster production and one was chosen for the Spirit Project logo. All contributing artists were recognized at the Spirit Forum on October 16, 2008. David Burns of Boonville, NY, pictured here with Spirit Project Director Marcey Dolgoff Alter, received a certificate of participation for his entry. David's submission was a beautiful photograph of an angel in his window formed by snow outside and the reflection of the glass.



Great Seal of the State of New York

**New York State
Developmental Disabilities
Planning Council**

2008 Annual Report

**For The 2nd Year
Of The 2007-2011 Five Year State Plan**

A Sampling of the...

Tracking Portfolio Review

By

Area of Emphasis

What are Tracking Portfolios?

Tracking Portfolios are investment tools to monitor and evaluate progress in target program areas. Originating from the field of finance, tracking portfolios provide a strategic focus for organizations to manage multiple grants, achieve program goals, and improve the process and outcome of program activities.

Employment

Goal: Reduce the unemployment rate and improve the relative employment/unemployment standing of adults with developmental disabilities when compared to the general public.

Goal Achievement:

The Partnerships for Youth grant was completed in 2008 with many individuals benefiting from the program. Over 200 youth were assisted in finding employment or other post-secondary education outcomes. While this particular grant came to an end in 2008, three other projects saw activity and will continue in the coming year.

Peer Mentoring grant activity assisted over 800 individuals in obtaining employment and more than 370 individuals were enrolled in One-Stop employment centers. The MISCC Employment project continued to address cross-systems barriers to employment for individuals with disabilities. This Committee has established a cross-systems agenda in five areas: facilitating access, training and credentialing on benefits planning and job coaches, marketing with employers, data analysis, and increasing public employment opportunities. Additionally, a Request For Proposal was issued for two more employment projects.

Information on employment outcomes for individuals with disabilities is being shared with other state agencies such as the Office of Vocational and Educational Services for Individuals with Disabilities (VESID) and the Office of Mental Retardation and Developmental Disabilities (OMRDD).

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/employment/employment_main.htm

Children's Services

Goal: Increase programmatic responsiveness and inclusion of children with developmental disabilities in education, early intervention, and child care programs.

Goal Achievement:

The area of traumatic brain injury interventions and supports saw substantial activity in 2008. Over 17,000 families and school personnel were trained on issues related to brain injuries and 17 students remained in integrated settings. While training initiatives made progress this year, there were also changes in policy—23 school policies were revised to further inclusion during this project year. More information can be found at http://www.bianys.org/learnnet/project_learn.html

Three additional activities saw continued effort in 2008 and will extend into 2009. These activities include our staff involvement with the Special Education Task Force, the New York State Afterschool Network, and the Commissioner's Advisory Panel on Special Education.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/childrens_services/childrens_ser_main.htm

Health

Goal: Expand appropriate and quality health care and related services available to children and adults with developmental disabilities.

Goal Achievement:

In 2008, the DDPC had multiple projects with ongoing activity in the area of Health. A collaborative activity for Nurses on developmental disabilities and aging trained approximately 670 health care professionals and direct service providers.

The impact of telemedicine approaches on health care was examined last year and resulted in a telemedicine demonstration. The intent of this grant is to increase availability and access to necessary health care services. The Telemedicine Project will provide cost/savings analysis and an assessment of healthcare delivery and satisfaction for individuals with disabilities in a variety of residential settings in the future.

In addition to developing oral health publications, the DDPC had two other ongoing projects related to dental health in 2008. The Oral Sedation Project trained 99 dentists in enteral sedation and 8 modules of the CD Modules Development Project were designed for dental residents.

Parent Partners in Health Education (PPHE) is a curriculum aimed at increasing medical residents' understanding of disability related issues. The main goals of this activity are to broaden knowledge about developmental disabilities, increase identification of developmental disabilities in children, and changing provider attitudes regarding individuals with developmental disabilities. As of December 2008, 371 residents have been trained as a result of this grant. In addition to training, 833 individuals with disabilities have been served by this project.

Health Care Transition is a grant aimed at easing the transition from pediatric to adult health care for individuals with disabilities 14-25 years of age. Over 150 consumers, caregivers, and providers have been trained on the topic of health transition. More information can be found at <http://www.HealthyTransitionsNY.org>.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/health/health_main.htm

Housing

Goal: Increase the housing and support options available to adults with developmental disabilities.

Goal Achievement:

The DDPC Housing Registry grant was completed in 2008 with 8,000 units listed and 40,000 users. This registry is a resource for individuals seeking accessible housing in New York State and can be found online at <http://www.nyhousingsearch.gov/>.

In collaboration with the Office of Mental Retardation and Developmental Disabilities, efforts with the NYC Resource Consortium led to 18 individuals transitioning into integrated living situations with 46 interns/advocates working on this effort. The purpose of this activity is to provide residential opportunities for individuals with disabilities in the New York area.

The Shared Living initiative, which is a partnership between the Developmental Disabilities Planning Council and the NYS Association of Community and Residential Agencies (NYSACRA), conducted 2 regional meetings—one in the Capital District and one in Western New York—to share information on the best approaches to shared living for individuals with disabilities.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/housing/housing_main.htm

Transportation

Goal: Decrease transportation-related barriers to participation in employment and community life.

Goal Achievement:

A collaboration with the Most Integrated Setting Coordinating Council (MISCC) addressed cross-systems barriers to transportation for individuals with disabilities in 2008 and this effort will continue in 2009. The MISCC Transportation Committee is addressing 3 areas: accessible taxis, county level mobility management, and state agency point of contacts. This collaboration is focusing on administering the Federal 5310 program which provides buses to not-for-profit agencies, disability sensitivity training for transportation operators, and encouraging local governments to increase transportation options.

Three DDPC projects have assisted approximately 8,500 people with transportation services and will continue assisting individuals with disabilities in 2009. The first activity included the creation of new bus routes so that workers can reach job sites that once were beyond reach by public transportation. The second activity was a training program to teach individuals with disabilities the skills needed to travel independently. Finally, transportation guides to inform individuals with disabilities about travel routes and options in their area were distributed.

For more information: http://www.ddpc.state.ny.us/pag_tracking_portfolio/transportation/transportation_main.htm

Quality Assurance - Protective/Preventive Services

Goal: Increase the number of children and adults with developmental disabilities who live in permanent family situations.

Goal Achievement:

At the 2008 Foster Care/LEND Conference 147 people were trained in issues related to children with developmental disabilities in foster care. Many recommendations were made by conference attendees including the development of standardized checklists to help physicians screen for developmental delays in children, the development of a standard electronic healthcare record that will follow children in foster care so that physicians have access to detailed records, and reform to regulations on article 16 and article 28 clinics which limit the number of appointments eligible for reimbursement per day.

DDPC has investigated use of a first responders training to address the issue of practice barriers in emergency preparedness planning. This is seen as necessary because the DDPC found that most responder training focuses on hearing impairments, vision impairments, and Alzheimer's disease with little time devoted to general disabilities. In response, the DDPC is developing a disability sensitivity and awareness training for first responders.

The DDPC also worked on a collaboration with the State Education Department (SED) on its Family Literacy Zones to improve existing literacy programs and create a comprehensive approach to literacy. This program hopes to help individuals with disabilities complete high school and either enter the workforce or begin work on a post-secondary education (college, university, trade school, etc.).

In 2008, the DDPC completed an Abuse Prevention grant focused on developing training resources on abuse prevention. An abuse prevention DVD (ESCAPE) was distributed to over 200 community programs. To obtain a free copy of the ESCAPE DVD contact the DDPC at 518-486-7505 or nrose@ddpc.state.ny.us Another grant completed in 2008 was the Independent Cross-Systems Living Training, which assisted over 212 staff in multiple areas on improving long term care for individuals with disabilities.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/protective_preventive_services/prot_preven_serv_main.htm

Quality Assurance - Advocacy and Leadership

Goal: Develop strong, cohesive developmental disabilities advocacy networking in New York State.

Goal Achievement:

This year the DDPC made substantial gains in the area of Advocacy and Leadership. The Partners-in-Policymaking program emphasizes “hands-on” training by policy-makers at all levels of government. Training areas include the legislative process, inclusive education, and employment. A Partners in Policymaking training yielded 51 new graduates and 100 previous graduates gathered to receive instructions on the development of regional projects. The Partners-in-Policymaking grant was able to fund a Long Island project incorporating materials in a distance learning format—this exceeded DDPC expectations.

In the area of Leadership, the DDPC involved over 300 youth in various leadership activities, 100 of whom we engaged in community service activities. Some of these activities include fund-raising for non-profit organizations/charities, volunteering at nursing homes and animal shelters, and food/book/toy drives. Participants have been collaborating with the New York State Youth Power Self-Advocacy initiative. Through the DDPC Youth Leadership projects, 280 individuals have participated in programs to develop leadership skills. The goal of this initiative is to develop a new generation of leadership and self-advocacy in New York State.

Additionally, the DDPC began its partnership with the New York State Sibling Network. On May 7, 2009 the DDPC plans to sponsor a conference with the National Institute for People with Disabilities on sibling issues to help guide future DDPC work on sibling issues.

The New York State Disabilities Advocacy Association and Network (NYSDAAN) is the result of more than 10 years of activities aimed at improving advocacy services in New York. In 2008, more than 380 people were trained in issues related to disability advocacy, there were 19 policy improvements, and 150 policymakers received information related to individuals with disabilities and advocacy.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/advocacy_leadership/advoc_lead_main.htm

Quality Assurance - Workforce

Goal: Increase the quantity and quality of individuals involved in the developmental disabilities workforce.

Goal Achievement:

The Everyday Heroes program is designed to highlight the remarkable impact direct support professionals have on the lives of individuals with disabilities. Individuals participating in the Everyday Heroes program are living more inclusive lives due to their participation in the program. This program works with direct support leaders, teaching them best-practice approaches to inclusion for individuals with disabilities. The benefit of professionals learning person-centered approaches reaches beyond the individual as once one professional is trained they are likely to encourage their peers in the workplace to focus on inclusion and person-centered planning.

In 2008, the DDPC was involved in additional projects related to workforce issues. The first project is the OMRDD Direct Support Professionals Advisory Board which is a cross-systems workgroup focused on issues related to the workforce. The second project involves the development of a New York chapter of the National Alliance for Direct Support Professionals (NADSP), named the Direct Support Professionals Alliance of New York State.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/workforce/workforce_main.htm

Quality Assurance - Self-Determination

Goal: Increase service system reliance on self-determination processes and person-centered planning.

Goal Achievement:

2008 saw the completion of DDPC work on person centered planning in state prisons. This project included a training DVD for corrections personnel and an updated special needs manual for correction officers. The project began by spending time in prisons and observing how person centered practices for inmates with developmental disabilities could best be introduced into this specific institutional setting. This activity helped infuse person centered practices into three special needs units in three New York State prisons.

Self-Determination is the act of an individual guiding—or determining—the course of their own life. The DDPC Self-Determination grant with the Self Advocacy Association of New York State (SANYS) is educating and training 500 individuals in self-directed service options and adding a Think Tank in NYC. This Think Tank project will work to promote new ideas about self-directed supports and community inclusion for individuals with DD living in New York City. Another grant with The Office of Mental Retardation and Developmental Disabilities (OMRDD) seeks to enable 100 individuals and families who have decided to seek a self-directed option to get the help they need through their regional Developmental Disabilities Services Office (DDSO).

The Office of Mental Retardation and Developmental Disabilities is working with 200 individuals on person centered planning through the OMRDD Real Choice Systems Change Grant. This partnership with OMRDD is in line with the DDPC goal to expand choices in life for individuals with DD.

Also, the New York State Nursing Home Transition and Diversion Medicaid Waiver Program is assisting about 40 individuals to ensure they receive the most appropriate care. The purpose of this activity is to transition individuals from institutional living back into the community, giving them more options in terms of lifestyle and supports. The Nursing Home Transition and Diversion Medicaid Waiver aligns with DDPC goals for Housing, Health, Self-Determination, and Community Supports. The DDPC sits on the advisory board of this Department of Health (DOH) waiver program and has provided feedback on structure, design, and policy.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/self_determination/self_deter_main.htm

Community Supports - Un/Under-Served Populations

Goal: Increase community capacity to include and serve children and adults with developmental disabilities from under-served populations.

Goal Achievement:

Prader-Willi Syndrome (PWS) is a birth defect caused by an abnormality on the 15th chromosome affecting both males and females equally. Symptoms of PWS include a chronic hunger that when left unchecked can lead to individuals becoming dangerously obese, decreased muscle tone, and an average Intelligence Quotient of about 70. The DDPC Prader-Willi Grant led to the development of a Prader-Willi Syndrome training curriculum in 2008. The curriculum includes an overview of PWS, information on how to screen for PWS, the symptoms of PWS, and information on the referral process for services and supports for individuals with Prader-Willi Syndrome. In addition to the curriculum development, this grant also led to a series of Prader-Willi screening clinics which trained 60+ physicians per session. Additional information on Prader-Willi Syndrome can be found on the Prader-Willi Association's website <http://www.pwsausa.org>.

DDPC staff serve on the Interagency Taskforce on Autism which is examining how to better provide lifelong services and support for individuals on the autism spectrum and their families. The DDPC also held two focus group sessions to discuss issues related to autism. Results of these conference calls were shared with the Office of Mental Retardation and Developmental Disabilities' Taskforce on Autism.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/underserved_population/und_pop_main.htm

Community Supports - Community Participation

Goal: Improve quality of life and community participation for children and adults with developmental disabilities, including participation in recreational, social and leisure activities.

Goal Achievement:

In 2008, the DDPC held a 2nd Annual Central New York Developmental Disabilities Services Office (CNYDDSO) religious needs conference. This conference brought together 100 individuals for an artwork awards ceremony and discussion of the DDPC congregational inclusion grant. Twenty-five individuals with developmental disabilities have expressed interest in participating in a congregation or pursuing other spiritual choices. By attending the conference, participants were able to help design aspects of the Congregational Inclusion project with their feedback. A training curriculum, *Spiritual Handbook* and the *Connecting People Through Faith*, was developed for direct support professionals to use in residential habilitation activities.

Programs related to aging and developmental disabilities progressed as 678 nurses, clinicians, and direct service providers were trained in 2008. The DDPC sat on the advisory board for this initiative since it began and helped with design, implementation, and course evaluation and modification. Additional information on this activity can be found at https://www.rrti.org/PDF/Nurse_Training_Brochure.pdf

Through the inclusive recreation grant with SUNY Cortland, 387 individuals have completed inclusion training and are now certified to assess sports and recreational facilities. As a result of this, about 250 recreation sites have been evaluated for inclusivity for individuals with disabilities. To keep individuals informed about this activity, a quarterly newsletter and online database listing accessible recreation sites is being developed. More information on this can be found at <http://www.cortland.edu/nysirrc/>.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/community_participation/community_part_main.htm

Cross Cutting

Goal: Assure that the service needs and quality of life for children and adults with developmental disabilities and their families are considered in policy and practice.

Goal Achievement:

The DDPC had ongoing activity in 2008 related to various cross-cutting issues. One project focused on Emergency readiness and another on ensuring that first responders have the proper training and knowledge to properly assist individuals with disabilities in an emergency situation.

Emergency readiness is critical for people with developmental disabilities living independently. People with developmental disabilities may have certain needs that may set them apart from their neighbors in the event of a disaster. Some individuals with disabilities may not be able to evacuate without assistance or know what to do or where to go for help or shelter in an emergency situation. This is why it is important to identify what supports are in place to address emergency situations as well as gaps and shortfalls in those systems including those that do not fully address the needs of people with developmental disabilities.

The DDPC has contacted multiple counties to determine if they have an emergency needs registry for people with disabilities. DDPC has also collected copies of forms from counties with a registry and reviewed them for appropriateness for individuals with disabilities. In the end, the DDPC determined that existing forms could use more language within to help identify the specific needs of people with developmental disabilities.

For more information: http://www.ddpc.state.ny.us/pages/tracking_portfolio/emerging_issues_community_education/emerging_issues_main.htm

A Sampling of DDPC Projects

in

2008

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Abuse Prevention & Decision Making

As an adaptation to the **ESCAPE** (*Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment*) curriculum, Teacher's College of Columbia University has developed an ESCAPE DVD abuse prevention training package for use by trainers with self-advocates. In addition to developing a training DVD for adults with DD, the project is providing technical assistance to community organizations using this curriculum and is also evaluating the effectiveness of the DVD. To obtain a free copy of the training package, contact the DDPC.

Aging & Developmental Disabilities

The DDPC remains actively involved in several activities that address issues related to services and supports for older individuals and their caregivers, including collaboration with the NYS Office for the Aging (NYSOFA), the Governor's Family Caregivers Council and the KinCare Coalition lead by AARP, which focuses in particular on grandparents raising children with disabilities. Information and resources funded under aging initiatives by the DDPC are also available at the SUNY Albany Center for Excellence in Aging Services at www.albany.edu/aging. The DDPC is also participating in the OMRDD Commissioner's Task Force on Aging & DD, as well as the Geriatric & DD Nurse Training Program administered by the Rehabilitation Research & Training Institute (www.rrti.org). In 2009, the DDPC will be implementing a residential telemedicine demonstration in the Capital Region with the Center For Disability Services (CFDS).

Everyday Heroes

The DDPC provided funding to eight community based organizations and one DDSO to assist OMRDD in expanding their Everyday Heroes leadership initiative statewide. These organizations have committed to infusing “best practice” approaches to creating inclusion throughout their residential and day services. These projects are also mentoring other regional agencies within their respective communities to infuse Everyday Heroes principles. An Everyday Heroes DVD and additional resource materials on the Everyday Heroes approach is available from OMRDD at

http://www.omr.state.ny.us/hp_everyday_about.jsp .

Hospice and Palliative Care

The DDPC has sponsored an expanded partnership between OMRDD, NYSARC, service providers and the Hospice & Palliative Care Association of NYS (HPCANYS). Hospice and NYSARC conducted regional cross-systems training across the state to facilitate access to appropriate hospice services for individuals with developmental disabilities regardless of residential setting. The Hospice training curriculum is available from NYSARC at www.nysarc.org . In addition, technical assistance is being provided to both the hospice and developmental disabilities service systems staff through <http://www.ddhospicepalliativecare.org/> .

Independent Cross-Systems Training

The DDPC supported regional cross-systems training to the NYS Office for the Aging State Long-Term Care Ombudsman Program (NYSLTCOP), the Department of Health (DOH) Regional Resource Development Specialists (RRDS), the OMRDD Pre-Admission Screening Resident Reviewers (PASRR), and local NY CONNECTS point-of-entry staff, to enhance the effective long-term care collaboration amongst these systems. The Center for Disability Rights in collaboration with the NY Association on Independent Living (NYAIL) implemented a curriculum that provided training to over 220 staff from all engaged service systems. The intent was to build the essential vision and networking necessary for successful implementation of the DOH Nursing Home Transition & Diversion Waiver. The curriculum and technical assistance is available from <http://rochestercdr.org/training/> .

Education Intervention and Planning for Students with Traumatic Brain Injury

DDPC developed LEARNet with the Brain Injury Association of NYS (BIANYS) to implement a statewide project that is providing intervention planning support and technical assistance to students with acquired traumatic brain injury (ATBI), their families and school personnel, with the benefit of allowing students to remain in the most-integrated educational setting. BIANYS conducted parent/family sessions to identify issues of concerns and barriers to educational and community inclusion. This resource is being used by school personnel to address functional barriers to learning regardless of disability. Information on this can be found on the BIANYS website at <http://www.bianys.org/learnet/>. The NYS OMRDD has provided long-term sustaining funds for this web-based resource through the BIANYS Family Advocacy, Counseling & Training Services (FACTS) program.

Partnerships for Youth

In collaboration with the NYS Department of Labor (DOL), employers, school districts/BOCES, the Office of Vocational & Educational Services for Individuals with Disabilities (VESID), the Commission for the Blind and Visually Handicapped (CBVH) and community-based service providers, the DDPC funded five Partnerships for Youth (PFY) projects. The intent of the initiative was to build local partnerships to increase the utilization of the One-Stop Employment & Training system by youth with disabilities, and to build a sustainable, multi-partner transition approach for school-to-work. Project outcomes resulted in over 2,400 students engaging in community-based activities, mentoring, work-study and training, with 200+ students transitioning to competitive employment or post-secondary education, and 450+ students enrolled in One-Stop centers. Most PFY pro-

ject school districts successfully enrolled in One-Stop centers. Most PFY project school districts successfully engaged in the VESID Model Transition Project initiative, which is reaching over 200 school districts and has the potential to serve over 12,000 students with disabilities. For more information on the Model Transition Program, go to: <http://www.vesid.nysed.gov/mtp/home.html> .

Peer Mentoring & Supports in Employment

This collaboration with VESID is supporting seven regional projects committed to providing employment-related peer supports to obtain, maintain and sustain employment outcomes. There is a major component on building connections for peer-based employment groups to maintain job-seeker engagement with the vocational rehabilitation system, including both VESID and the Commission for the Blind & Visually Handicapped (CBVH). In addition, building connections with the One-Stop service system is also essential to project outcomes and the Department of Labor is also a partner in this initiative. To date, projects have used approximately 120 peer mentors who have assisted over 312 individuals to obtain and maintain employment, over 56 new Individualized Plans for Employment (IPE) have been developed, and more than 123 people have achieved employment.

Resource Consortium of New York City

In providing matching project funds to OMRDD and the NYC Regional Office, the DDPC is supporting four community-based agencies to explore ways of increasing individualized service opportunities in New York City. These agencies (AHRC-NYC, HeartShare, Sinergia, and UCP-NYS) have committed to working with self-advocates, families and housing system representatives to assist people to enhance their choice and community inclusion. Agencies have committed to hiring housing advocates through the OMRDD Employment Training Program (ETP) and to assist 10 people each in accessing smaller, individualized living environments over a two-year period. To date, more than 15 people have transitioned to more integrated and inclusive settings.

Shared Living

The DDPC implemented a project with the NYS Association of Community & Residential Agencies (NYSACRA) to coordinate a strategic planning process around the concept of Individualized Shared Living in New York. NYSACRA conducted a statewide forum on the issue and will be coordinating five to six regional discussions in 2009 with the intent of bringing together individuals, family members, OMRDD staff, and residential providers for dialogue on issues, barriers and strategies to increasing individual residential options. Shared Living basically means that people get to increase the choice and autonomy over where, how and with whom they will live. For more information on this project contact NYSACRA at www.nysacra.org

Transportation & Employment

The DDPC is funding three grants intended to demonstrate how effective collaboration can address transportation barriers to employment. Projects are collaborations between local transportation providers, the One Stop Employment Centers and community based organizations. Project activities have included the creation of new transportation routes, provision of travel training, dispatch coordination, route planning, passenger surveys, driver training, information dissemination, etc. For more information contact:

**[The Developmental Disability Alliance of Western New York
Oswego Counties Opportunities, Inc.
Franklin County Public Transportation](#)**

Youth Leadership

The DDPC is funding six organizations to develop self-advocacy and leadership skills for youth with developmental and other disabilities and to then implement community relevant service projects that will facilitate both community inclusion as well as personal/community leadership. These six organizations are taking varied approaches to leadership development. Over 374 youth have been engaged in leadership activities **and** community “pay it forward” projects. All projects have committed to disseminating their leadership curricula and approaches to self-advocacy and community engagement.

New York State Disabilities Advocacy Association & Network (NYS DAAN)

After more than 10 years of sponsoring a wide range of capacity building initiatives to strengthen advocacy services throughout the state, the New York State Disabilities Advocacy Association and Network (NYS DAAN) has been effectively launched. The goal of the association is to provide linkages and resources for all organizations providing advocacy services to

individuals with disabilities and their caregivers. Project achievements in 2008 included convening a Statewide Advocacy Forum. The Forum provided a venue for cross- systems networking among advocates and organizations and sharing best practices, tools, and resources. NYS DAAN also spent considerable time working on membership recruitment including advocates, services providers, and organizational members. As a result of NYS DAAN activities, over 380 people were trained in some aspect of advocacy, over 19 policy improvements resulted, and over 150 policymakers received disability and advocacy related information.

Parent Partners in Health Education (PPHE)

DDPC is providing funding to 16 New York State residency programs to replicate a multi-component curriculum which focuses on increasing the sensitivity, awareness, and exposure of Medical Residents to individuals with developmental disabilities and the issues faced by these individuals and their caregivers. The core feature of this project includes caregivers and individuals with developmental disabilities serving as one of the primary educators of the participating residents. Each resident is partnered with a family or an adult living within a residential program who teaches the medical resident about daily life for the family and the individual with a developmental disability. Residents are encouraged to meet with the caregivers and individual with a disability in the family's home or residential program as well as accompany the caregivers to a community meeting such as a Team Meeting or Committee on Special Education meeting.

Residents participate in a series of educational lectures, community medicine case presentations, clinical experiences and small group discussions. The DDPC is working with the Department of Health's Council on Graduate Medical Education, to evaluate the curriculum implementation and potential replication in other residency programs. Project achievements in 2008 have included over 570 medical and community based agency personnel being trained. Of those trained, over 370 primary care residents were educated by this effort. In addition, over 883 children and adults have been served by some aspect of the PPHE project.

Health Care Transition

In 2006, DDPC awarded a grant to SUNY Upstate Medical Center in Syracuse to establish an Institute for Training on Health Care Transitioning. The Institute provides statewide expertise, training, and resources on youth with developmental disabilities, ages 14-25, as they transition from pediatric to adult health care. The Institute has developed a curriculum for youth, their caregivers, and physicians, including a toolkit, and an interactive website that includes checklists to determine health transition readiness, goal setting tools to define roles and set priorities during the transition process, and a search engine for accessing transition-related services and service coordination in New York State. The website for the Health Transitions Training Institute is now live and accessible at www.HealthyTransitionsNY.org. As of December 2008, over 150 consumers, caregivers, and providers have been trained on the topic of health transition.

Middle School Socialization

Best Buddies New York received a grant in the fall of 2006 to establish and support a statewide model to foster friendship opportunities for middle school aged youth with and without disabilities. The goal of the project is to pair middle school students with and without disabilities and have students actively participate in a variety of leisure, social, and recreation activities. Project achievements in the 2007- 2008 academic (school) year included the establishment of over 27 active chapters with 6 new chapters of Best Buddies in development in various regions of the State. As of December 2008, over 900 youth with and without disabilities have been served by this initiative.

Adoption and Foster Care

In January of 2007, DDPC launched grants with New York State Citizen's Coalition for Children (NYSCCC) and New Alternatives for Children (NAC) to provide mechanisms to ensure that foster and adoptive families and caregivers of children with developmental disabilities have access to and receive information on training and other supports. The funded organi-

zations have provided information and referral to community resources for foster and adoptive families, as well as provided training on topics related to foster care, adoption, and special education. The grantees have developed a variety of informal supports including an “800” information line, internet based interactive forums, listserves, and regional parent support groups. To date, approximately 300 families have received information, training and supports.

Children Who Are Medically Fragile

In April of 2008, four agencies: United Cerebral Palsy of New York City, The Children’s Hospital at Montefiore, Visiting Nurse Regional Health Care System, and St. Mary’s Healthcare System for Children, launched projects designed to address the needs of children who are medically fragile. The project models are designed to provide training for nurses, develop a care coordination model addressing transition from a hospital setting to a home or community setting, develop a care coordination model using the concept of a medical home, and develop an advocacy training program for parents of children who are medically fragile. Collectively, the projects have trained over 90 families and community based providers on various issues for individuals who are medically fragile.

Prevention of Fetal Alcohol Spectrum Disorders (FASD)

DDPC awarded a grant to the American College of Obstetricians and Gynecologists District II/NY (ACOG) to launch a statewide public awareness campaign in January of 2009, which will focus on the prevention of Fetal Alcohol Spectrum Disorders (FASD). The intent of this initiative is to educate women with and without disabilities of childbearing age about the dangers of alcohol use during pregnancy and offer essential methods to prevent FASD. ACOG will also distribute educational toolkits about FASD prevention across the State.

Partners-In-Policymaking

The New York State Partners-in-Policymaking Program follows the model developed by the Minnesota Governor's Council on Developmental Disabilities. The DDPC funded The Advocacy Center to implement this comprehensive curriculum that provides essential advocacy information and skills to people with developmental disabilities and their families. Participants in this program receive "hands-on" training from policymakers and experts at the local, state and Federal levels in areas including the legislative process, community building, inclusive education, housing and employment. In 2008, another 36 individuals with developmental disabilities and family members statewide graduated from this program. Additionally, 20 individuals from the Long Island region participated in a pilot program which provided an abbreviated training in a distance learning format.

Self-Determination

The DDPC is providing funding to the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) and the Self-Advocacy Association of New York State (SANYS) to continue their efforts to create a sustainable structure for the Self-Determination Program as well as to expand the self-directed options that individuals with developmental disabilities can use. The essence of self-determination is giving people with developmental disabilities the freedom to make choices and decisions regarding their lives. Individuals who live self-determined or self-directed lives have control over the services and supports they receive and determine who provides such services and supports. The project provides comprehensive and ongoing training as well as technical assistance to support people with developmental disabilities and families. Since the program's inception in 2002, over 370 individuals are benefitting from individualized plans and over 200 more are working with start-up brokers to formulate such plans. OMRDD has also been working with voluntary agencies to promote an Agency with Choice (AWC) model which will allow for more self-direction while maintaining a connection to a service provider.

Person-Centered Planning For Inmates with Developmental Disabilities

The DDPC is funding the Cornell University Employment & Disability Institute to establish a process that will integrate person-centered practices into the rehabilitation and release planning for inmates with disabilities in the NYS Department of Correctional Services (DOCS) and the NYS Division of Parole (DOP). The goals of the project are to enhance services provided to inmates with disabilities by DOCS and DOP in three Special Needs Units - Wende, ArthurKill and Sullivan. It is anticipated that the use of person-centered planning to the provision of services within DOCS and the development of appropriate releases by DOP will lead to a productive and habilitative incarceration for inmates with disabilities and significantly reduce recidivism rates.

Congregational Inclusion

The DDPC, in collaboration with the OMRDD Central NY Developmental Disabilities Services Office (CNY DDSO), initiated a project with the Consortium on Innovative Practices (CIP) to include religious/spiritual consideration in the Individualized Service Plan (ISP) process. The ISP is the cornerstone for laying out the services and supports that a person will need for an inclusive, productive and connected life. Spiritual connection plays a major role in the lives of many individuals. The DDPC project will provide technical assistance as well as document the obstacles, success and other considerations faced by individuals with developmental disabilities, their families, the service delivery system and individual congregation when these individuals express a religious preference or spiritual desire. A training curriculum and the *Spiritual Handbook* and the *Connecting People through Faith* were developed for direct support professionals and are being utilized by service coordinators and residential habilitation plan writers. Evaluation tools and a website have also been developed.

Oral Health

In collaboration with the OMRDD Task Force on Special Dentistry, the DDPC has funded two projects under this objective. One is for the creation of a series of PowerPoint lectures on CD with an accompanying manual as well as a teacher's handbook to help increase access to care by educating and familiarizing dentists with the special needs of patients with developmental disabilities. The 8-training modules will help enable dentistry residents to better treat individuals with developmental disabilities. The topic areas of the modules include an introduction to developmental disabilities, genetics, legal and ethical issues, treatment planning, neuromuscular disorders, learning disabilities and mental retardation, seizure disorders and autism. It is hoped that the dentists who receive this training will increase treating patients with special needs in their practice. The modules will be available on CD for NYS dentistry residents and will also be housed on a yet to be determined website. The 2nd project is a continuing education training for dentists in modern enteral sedation methods. Already 99 dentists have received the training and were certified. The trained dentists will be listed on the OMRDD web page as dentists willing to treat persons with developmental disabilities.

Individualized Supports Learning Institute (Quality Assurance)

The DDPC has funded the NYS Association of Community & Residential Agencies (NYSACRA) to increase provider capacity to assist individuals with developmental disabilities in implementing more self-directed options. The institute has created a learning community with currently 12 provider agencies that wish to learn and explore avenues to deliver individualized services and supports while ensuring their financial stability. Each agency is seeking to help 10 individuals.

Recreation

The DDPC is providing funding to the State University of New York at Cortland to establish a sustainable statewide University-based Inclusive Recreational Resource Center that promotes inclusive recreation, sports and leisure activities. The NYS Inclusive Recreational Resource Center (NYS IRRC) has developed inclusivity tools used to assess recreational entities and programs for inclusion in New York State. "Inclusion U," the inclusivity assessment training, teaches the foundations of inclusion and accessibility while preparing participants to use the assessment tools to assess sites. Almost 350 individuals from different interested parties (including recreational professionals as well as a number of students and professors in 6 colleges) have been trained resulting in 250 sites being assessed for inclusivity. Train-the-trainer protocol has been developed and two professors from Corning Community College and Ithaca College were trained so that they can provide Inclusion U training to their respective students. Lehman College incorporated the Inclusion U into a three-credit graduate level course at their school. The IRRC held its first professional recreation referral service training this past year where dedicated therapeutic recreation professionals agreed to volunteer as recreation resources for people with disabilities in their region. A quarterly newsletter is being produced as well as a website and database of assessed recreational sites.



**New York State
Developmental Disabilities Planning Council
(DDPC)**

Grant Funding Guidelines

The New York State Developmental Disabilities Planning Council (DDPC) is a federally funded state agency working under the direction of Governor David A. Paterson. The DDPC is responsible for developing new ways to improve the delivery of supports and services to New Yorkers with developmental disabilities and their families.

The DDPC affects positive systems change through grant programs. The impetus for the grant programs is the core of the DDPC State Plan. The current State Plan, 2007-2011, is based on DDPC's commitment to ensuring that individuals with developmental disabilities and their families will have the opportunity to make choices in all aspects of their lives - about where and with whom they live, about the kind of school and/or work activities they participate in, about the health care they seek and receive, about the kinds, amounts, and source of supports they require and desire, and about the people who assist them in their lives.

To assist in understanding the *Grant Funding Guidelines* at the DDPC, the following documents provide a roadmap:

- *How a Concept Becomes a Grant* - where concepts for grants come from and how the process is conducted both within and outside of the DDPC.
- *Request for Proposal (RFP) Process* - the typical process that the DDPC uses to provide funding.
- *Unsolicited Proposals* - the nature of unsolicited proposals and how they are handled within the DDPC structure.

The preceding documents along with the DDPC State Plan, are available by contacting the DDPC at:

New York State Developmental Disabilities Planning Council
155 Washington Avenue—Second Floor
Albany, NY 12210
518-486-7505

- or -

Email: ddpc@ddpc.state.ny.us

- or, available online at -

Website: www.ddpc.state.ny.us



**New York State
Developmental Disabilities Planning Council
(DDPC)**

How a Concept Becomes a Grant

- Step 1** **Concept:** Comes from a variety of sources (self-advocates, families, system partners, etc.).
- Step 2** **Standing Committee**
- a) Review and consider idea (s).
 - b) Determine relevance to State Plan, portfolio, and Standing Committee objectives.
 - c) Assign, (or establish) a workgroup for further study and refinement (where applicable).
 - d) Develop set aside recommendation and refer to Executive Committee.
- Step 3** **Executive Committee**
- a) Review recommendation for set aside and relevance to overall State Plan.
 - b) Suggest changes or refinements (optional) to recommendation.
 - c) Identify where coordination is needed across Standing Committees and with other agencies.
 - d) Approve set aside or send back to Standing Committee for further work.
 - e) Refer approved set aside recommendation to DDPC.
- Step 4** **DDPC**
- a) Review set aside recommendation.
 - b) Provide additional comments (optional).
 - c) Approve set aside or send back to Standing Committee for further work.
 - d) Refer to Standing Committee to develop a Request for Proposal (RFP).
- Step 5** **Standing Committee**
- a) Develop and disseminate Request for Proposals (RFP).
 - b) Review and rate resultant proposals (with the assistance of outside reviewers and DDPC members, where appropriate).
 - c) Recommend specific proposals/applications for funding. *
 - d) Refer to Executive Committee.
- Step 6** **Executive Committee**
- a) Review funding recommendation (s).
 - b) Provide input for refinement (optional).
 - c) Approve funding recommendations or send back to Standing Committee.
 - d) Refer approved funding recommendation (s) to DDPC.
- Step 7** **DDPC**
- a) Review funding recommendation (s).
 - b) Provide input for refinement (optional).
 - c) Approve funding or send back to Standing Committee.
- Step 8** **Standing Committees and Grants Management Unit**
- a) Initiate performance agreements and contracting process to establish grant (s).
 - b) Develop and negotiate Performance Indicators.
 - c) Provide technical assistance to grantees.
 - d) Monitor programmatic and fiscal process.

*For continuation funding for established grants, the process begins at Step #5 with review of progress toward meeting grant objectives in the prior funded year (s).



**New York State
Developmental Disabilities Planning Council
(DDPC)**

Unsolicited Proposals

Purpose

DDPC does not encourage unsolicited proposals.
Received proposals will be considered equally in accordance with the policy.

Policy

An unsolicited proposal is a proposal that is not a direct response to a Request for Proposal (RFP) issued by DDPC. Unsolicited requests for funding are not encouraged. However, individuals or groups are free to submit relevant and innovative issues to the DDPC at anytime for consideration developing future RFP's.

Procedure

In the event that DDPC does receive an unsolicited funding request, the following procedure will be applied:

- 1.) All unsolicited proposals should be logged into a master list that includes the date received and the name of sender.
- 2.) All such proposals should then be forwarded to the DDPC Executive Director.
- 3.) The Executive Director will review the request and forward it the appropriate staff member of the Standing Committee, dealing with the addressed issue, or to the Executive Committee for action consistent with procedural note 5.
- 4.) The Executive Director will send a letter to the applicant acknowledging receipt of the proposal.
- 5.) The designated staff member will then bring the proposal to the attention of the Chair of the Standing Committee and one of the following determination will be made:
 - The proposal does not relate to DDPC's current priorities;
 - The proposal relates to DDPC's current priorities, but needs to be resubmitted when and if the Committee issues an RFP for the addressed topic stated in the proposal;
 - The proposal relates to DDPC's current priorities, and has merit, but the addressed issues stated in the proposal need to be further evaluated by the Committee; or,
 - The proposal is recommended to the Executive Committee as a sole source grant, demonstrating exceptional and compelling circumstances and validity of any other organization to successfully engage in such an endeavor.
- 6.) The Executive Director will send a letter to the applicant, after one of the above determinations has been made, informing her/him the outcome of the request.
- 7.) The date of the letter and the determination will be logged into the DDPC system.



**New York State
Developmental Disabilities Planning Council
(DDPC)**

Request for Proposal (RFP) Process

The New York State Developmental Disabilities Planning Council (DDPC) typically provides project funding through the use of a formal Request for Proposals (RFP) process. Workgroups supported or established by the DDPC explore the needs of individuals with developmental disabilities and identify projects that have the potential to spur capacity building and/or systems change. The current DDPC State Plan drives all activities. Once a worthwhile project has been identified and loosely designed, the RFP process begins. The following list outlines the RFP process for choosing the organizations to implement a DDPC funded project.

- The DDPC defines a funding opportunity and sets aside sufficient funds to support a targeted initiative consistent with objectives in the current DDPC State Plan.
- Based on the needs identified by a workgroup, an RFP is authorized by the DDPC and is developed by DDPC Members, staff and key system stakeholders. Stakeholders who might want to apply for such an opportunity are precluded from working with the workgroup and/or on the RFP.
- The RFP is sent out to a targeted mailing list of agencies that meet the eligibility criteria for the specific RFP. The RFP is also posted in the New York State Register and on the DDPC website to ensure access to the RFP. Key partners are encouraged to disseminate the RFP and provide web-links to interested and appropriate parties.
- Letters of intent are typically requested from agencies that are interested in applying for the grant. The number of letters received is an indication of the number of applicants. The number of letters of intent received helps DDPC staff in selecting the appropriate number of reviewers, including council partners and consumer members.
- Proposals are accepted by the DDPC as long as they are received by the deadline and are completed in the format specified within the RFP.
- Proposals are distributed to reviewers. A minimum of three external reviewers with knowledge in the field relevant to the project are selected. Several DDPC staff members will also read and rate each proposal, but the scores of the staff members are usually combined into one composite score for each proposal and are not given undue weight in decision making activities.
- Five sections of the proposal are considered and scored by the reviewer:
 1. Plan of Action
 2. Project Timelines, Milestones and Products
 3. Project Evaluation, Continuation and Sustainability
 4. Applicant Capability, Personnel and Resources
 5. Proposal Budget and Cost

...continued...



**New York State
Developmental Disabilities Planning Council
(DDPC)**

Request for Proposal (RFP) Process...continued

Reviewers are asked to provide comments about the strengths and weaknesses of each proposal. The points are totaled from all four sections resulting in a composite score.

- The scores produced by the reviewers for one particular proposal are then averaged. This averaging is done for all proposals received. The DDPC has noted over time that proposals rated below 80 are unlikely to produce the desired results and are unlikely to be funded.
- The strengths and weakness of the higher scoring projects are considered among all the readers until consensus is reached on which proposals are to be recommended to the DDPC for funding.
- The DDPC typically considers geographic and/or cultural diversity and differences in ways of addressing a common problem and/or long term sustainability in making final funding recommendations and awards.
- RFP recommendations are then reviewed with approval sought from the DDPC Standing Committees, Executive Committee and full Council at their respective quarterly meetings.

Acronym Listing

- **AARP...American Association of Retired People**
- **ACS...Administration for Children's Services**
- **AT...Assistive Technology**
- **ATBI...Acquired Traumatic Brain Injury**
- **BIANYS...Brain Injury Association of New York State**
- **BIP...Behavior Intervention Plans**
- **BOCES...Board of Cooperative Education Services**
- **CBVH...Commission for the Blind and Visually Handicapped**
- **CQCAPD...Commission on the Quality of Care and Advocacy for Persons with Disabilities**
- **CSS...Consolidated Support and Services**
- **DD...Developmental Disabilities**
- **DDPC...Developmental Disabilities Planning Council**
- **DDSO...Developmental Disabilities Service Office**
- **DHCR...NYS Division of Housing and Community Renewal**
- **DME...Durable Medical Equipment**
- **DOCS...Department of Correctional Services**
- **DOH...Department of Health**
- **DOL...Department of Labor**
- **DOP...Division of Parole**
- **ESCAPE...Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment**
- **FBA...Functional Behavioral Assessment**
- **HPCANYS...Hospice and Palliative Care Association of New York State**
- **LEARN...Living Education and Resource Network**
- **MFP...Money Follows Person**
- **MISCC...Most Integrated Setting Coordinating Council**

Acronym Listing

(continued...)

- **OMRDD...Office of Mental Retardation and Developmental Disabilities**
- **NYAIL...New York Association on Independent Living**
- **NYSACRA...New York State Association of Community Residential Agencies**
- **NYSARC...New York State Association of Retarded Children**
- **NYSDAAN...New York State Disabilities Advocacy Association & Network**
- **NYSLTCOP...NYS Long Term Care Ombudsman Program**
- **NYSOFA...New York State Office for the Aging**
- **PASRR...Pre-Admission Screening Resident Reviewers**
- **PCP...Primary Care Providers**
- **PFY...Partnership for Youth**
- **SANYS...Self-Advocate Association of New York State**
- **SED...State Education Department**
- **SD...Self-Determination**
- **SOFA...Office for the Aging**
- **RFP...Request for Proposal**
- **RRDS...Regional Resource Development Specialist**
- **TBI...Traumatic Brain Injury**
- **UWR...United We Ride**
- **VESID...Vocational and Educational Services for Individuals with Disabilities**



New York State Developmental Disabilities Planning Council

LOOKING FOR DEDICATED ADVOCATES

The New York State Developmental Disabilities Planning Council (DDPC) is a governor-appointed body of 31 people in the following categories: people with developmental disabilities; parents, guardians or relatives of people with disabilities; and agency representatives. Funded through the Federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act), the Council seeks to assist New Yorkers with developmental disabilities. Because Council members terms are limited, there are vacancies available for consumer and family members most years.

WHAT ARE THE COUNCIL'S PRIORITIES

To help New Yorkers with developmental disabilities, as defined by the DD Act, receive the services and support programs necessary to achieve personal independence, community integration, and increased productivity. The DDPC is an advocate for the people, with the intention of creating choices for people with developmental disabilities. The areas of priority for the DDPC, include: educational and early intervention services and reform; health care; community based living; employment; access to services; and training in responsibility and inclusion for people with developmental disabilities.

WHAT ARE THE COUNCIL MEMBER'S RESPONSIBILITIES

To attend quarterly DDPC meetings and various standing committee program meetings in the Capital District. This gives members an opportunity to review Council policies, hear presentations by agency personnel and grantees, and offer their views and insight on pertinent issues. The Council has an Executive Committee and three standing committees.

The Council members serve an integral role in the DDPC's grant funding initiatives through their communication and involvement with local community organizations and businesses seeking to develop and implement such worthwhile programs.

DISABILITY

A developmental disability is a severe, chronic disability of a person which: is attributable to a mental or physical impairment or combination of mental and physical impairment; is manifested before the person attains age twenty-two; is likely to continue indefinitely and results in substantial functional limitation in a person's self-care, mobility, learning, capacity for independent living and economic self-efficiency.

The person would need a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated. Except that such term would apply to infants and young children up to age five, who have substantial development delay or specific congenital or acquired conditions with a high likelihood of resulting in developmental disabilities if services are not provided.

DDPC INITIATIVES

The DDPC fulfills its responsibilities under the DD Act principally through the development, implementation and evaluation of its State plan. The plan describes a variety of strategies to be used to accomplish its goals of systems change, capacity building and advocacy on the part of people with developmental disabilities and their families. The strategies include demonstration of new approaches, outreach and training funded by the DD Act grant allocations and implemented through the efforts of the Council members and staff.

IF YOU ARE INTERESTED

Please answer, in brief, the questions listed on the reverse side of this form and return the completed document to the address listed. Thank you for your time and consideration of this matter. The DDPC looks forward to hearing from you in the near future.

GENERAL QUESTIONNAIRE

NAME: _____

SOCIAL SECURITY NUMBER: _____

HOME ADDRESS,
PHONE NUMBER & EMAIL: _____

PRINCIPAL OCCUPATION: _____
Please attach resume if appropriate

ACTIVE PROFESSIONAL &
SOCIAL AFFILIATIONS: _____

WHAT YOU BELIEVE YOU CAN OFFER AS A MEMBER OF THE DDPC:

The DD Act states, "Not less than 60% of the membership of each State Council shall consist of individuals who are: Individuals with developmental disabilities; parents or guardians of children with developmental disabilities; or immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves; and (are) not employees of a state agency that receives funds or provides services under (the DD Act); and who are not managing employees of any other entity that receives funds or provides services under (the DD Act)."

PLEASE EXPLAIN THE CHARACTERISTICS AND SITUATION WHICH QUALIFIES YOU FOR COUNCIL MEMBERSHIP:

By virtue of this correspondence and my signature below, I indicate my prospective interest in serving as a member of the New York State Developmental Disabilities Planning Council. I understand this is a voluntary interest survey, and I am aware Council members are appointed and serve a term selected by the Governor.

SIGNATURE & DATE: _____

New York State Developmental Disabilities Planning Council

155 Washington Avenue / Second Floor—Albany, NY 12210

1-800-395-3372

George E. Fertal, Sr., *Chairperson*

Sheila M. Carey, *Executive Director*

Rose Marie Toscano, *Vice-Chair*

New York State DDPC Staff

Hon. Sheila M. Carey

Executive Director

Staff

Nathaniel Douglas

James Huben

Karen Jackuback

Lynn King

Tom Lee

Anna Lobosco

Ellen Meyers

Tom Meyers

Nick Rose

Marybeth Stoddard

Kerry Wiley

Sharon Winchester

Russ Wise

Robin Worobey

Program Associates / Internships

Katie Anderson

Deborah Chapin

Patrick DiStefano

Benjamin Fifield

John McDonald



Great Seal of the State of New York

New York State Developmental Disabilities Planning Council

**155 Washington Avenue
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Annual Report ***2008***

10-01-07 / 09-30-08