



**New York State
Developmental Disabilities
Planning Council**

(NYS DDPC)

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Great Seal of the State of New York

**New York State
Developmental Disabilities
Planning Council**

(NYS DDPC)

*Annual
Report
2010*

10-01-09 / 09-30-10

**The
New York State
Developmental Disabilities Planning Council
(NYS DDPC)
is a federally funded state agency.**

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.

Patricia Edelstein

Chairperson

Rose Marie Toscano

Vice-Chairperson

Trish Washburn

Consumer Caucus Chairperson

Sheila M. Carey

Executive Director



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**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.**

New York State DDPC Members

Patricia Edelstein, Chairperson

Consumer Member

Rose Marie Toscano, Vice-Chairperson

Consumer Member

Michelle Appleby

Consumer Member

Ansley Bacon, Ph.D.

Director, University Centers for Excellence Member

Elizabeth R. Berlin

Deputy Commissioner, NYS Office of Temporary and Disability Assistance

Hon. Michael J. Burgess

Director, NYS Office for the Aging

Hon. Courtney Burke

Acting Commissioner, NYS Office For People With Developmental Disabilities

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

Shirley Goddard

Consumer Member

Kevin Kennedy

Consumer Member

Hon. Dr. John B. King, Jr.

Commissioner, NYS Education Department

Aldea LaParr

Consumer Member

Barbara Levitz

Consumer Member

Continued...

New York State DDPC Members...continued

Lawrence Lieberman	<i>Consumer Member</i>
Hon. Roger Bearden	<i>Commissioner, 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>
Hon. Joan McDonald	<i>Commissioner, NYS Department of Transportation</i>
Hon. Greg Olsen	<i>Acting Director, Office for the Aging</i>
Wendy P. Orzel	<i>Consumer Member</i>
Cliff Perrin	<i>Consumer Member (ex officio)</i>
Rain Rippel	<i>Consumer Member</i>
Ann L. Scherff	<i>Consumer Member</i>
Beatrice Schmidt	<i>Consumer Member</i>
Hon. Nirav R. Shah, M.D., M.P.H.	<i>Commissioner, NYS Department of Health</i>
Stephen B. Sulkes, M.D.	<i>Director, University Centers for Excellence Member</i>
Hon. Darryl C. Towns	<i>Commissioner & C.E.O., NYS Division of Homes and Community Renewal</i>
Trish Washburn	<i>Consumer Member</i>

**New York State
Developmental Disabilities
Planning Council**

~ Staff ~

Hon. Sheila M. Carey
Executive Director

Nathaniel Douglas

James Huben

Karen Jackuback

Thomas Lee

Kathleen Leggiero

Anna Lobosco

Ellen Meyers

Tom Meyers

Marybeth Stoddard

Kerry Wiley

Robin Worobey

Program Associates / Internships

Nicole Bak

Benjamin Fifield

Nick Hobson

John McDonald

Ashley Pacelli

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) 2010.

2010 marks the fourth year of our *2007-2011 Five-Year State Plan*. The **DDPC**, in conjunction with our grantees, has 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 2010 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 regularly 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 2010 Annual Report is a review of the DDPC Goal Achievements which monitors the progress toward meeting our goals and objectives. We would also like to share with you some exceptional accomplishments of the DDPC for 2010 that reflect our grantees efforts in bringing our State Plan goals and objectives to fruition.

Continued...

A message from the...

Chairperson and Executive Director (Continued)

2010 marked the 41st anniversary of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). Originally authorized in 1963, the DD Act was reauthorized in 1970 and again every several years until its most recent reauthorization which was enacted on October 30, 2000. The next Congressional reauthorization is scheduled for the 112th 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 and is the genesis of the State Councils on Developmental Disabilities.

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 2011 we all are still facing a global economic crisis that continues to affect each of us in many ways. We constantly review 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 severity of the current economic environment.

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

Sincerely yours,



Patricia Edelstein
Chairperson



Sheila M. Carey
Executive Director

Facts & Figures

for...

2010 NYS DDPC Funded Programs

***Working together
for a future that works***

**...for all New Yorkers
with developmental disabilities
and their families.**

With \$4,374,416 the DDPC did the following...

- **15,423...Individuals / Families Benefited**
- **85...Programs / Policies Created**
- **\$9,279,279...Was leveraged**
- **\$2,527,582...Grantee Matching Funds**
- **20,311...People Involved in DDPC Funded Training**
- **1,925...People Active in Advocacy & Change Efforts***
- **440,447...Members of the General Public Reached**
- **123...Products Developed**
- **343...Products Distributed to Policymakers**
- **87,739...Products Distributed to general public**

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



The Great Seal of the State of New York

**New York State
Developmental Disabilities
Planning Council**

***Telling Our Story
Through
Our
Grant Programs***

The following “stories” reflect the depth and value of investment in grant programs from the New York State Developmental Disabilities Planning Council (NYS DDPC).

For more information on DDPC grant programs please contact the following Program Planners...

- **Adult Issues Committee**

Karen Jackuback

**Program Planner
518-402-3480**

- **Children’s Issues Committee**

Robin Worobey

**Program Planner
518-402-3478**

- **Systems Coordination
&
Community Education Committee**

James Huben

**Program Planner
518-402-3482**

• **Parent Partners in Health Education (PPHE)**

Children's Issues Committee (CIC)

Recognizing the need to improve the disability related skills and knowledge of primary care doctors, in 2005 the DDPC funded sixteen medical residency programs to integrate a disabilities-based curriculum into the core training provided to future doctors. Primary care physicians, including family physicians, pediatricians and internists, play a critical role in screening for developmental disabilities and identifying and coordinating resources for these individuals and their families. Currently however primary care medical residents receive very limited direct exposure to individuals with developmental disabilities and their families, lack an understanding of how a disability affects a family and have inadequate knowledge about community resources.

Receiving approximately \$26,000 per year, the residency programs participated in *Parent Partners in Health Education (PPHE)* curriculum which consists of a series of interviews between resident physicians and caregivers of individuals with developmental disabilities. The purpose of the caregiver interviews is to help the medical residents gain an understanding of the experiences of raising a child with a disability from the perspective of the family and the strengths and needs of adults who live in residential programs. Residents also participated in a series of didactic lectures, community medicine case presentations, community agency visits, clinical experiences and small group discussions.

While over 750 future primary care doctors participated in PPHE, the most significant impact of this initiative was the cultural change that took place within the participating residency programs. Program administrators and residents alike recognized the value of the curriculum and continue to implement PPHE beyond the DDPC funding cycle. Additionally, the NYS Council on Graduate Medical Education (COGME), the entity charged with overseeing medical residency training programs within New York State, is currently reviewing the outcomes of this initiative for possible implementation in all primary care residency programs in New York State.

Primary Care medical residents who participated in PPHE had the following to say:

“I think the biggest thing I took away from the experience was what an impact the words and tones a physician uses when giving a diagnosis has on the family and their general outlook toward the medical profession as a whole.”

“Parents really want their primary care physician to be familiar with community resources. This is covered in our readings and lectures, but it somehow sinks in more when I hear it from a parent.”

- **April Dixon: Parent Advocacy Success Story**

Children's Issues Committee (CIC)

April Dixon remembers being very hesitant to speak up at Committee on Special Education meetings for her son, Jacob. When she was given an opportunity to speak, she would just tell a cute story about Jacob, and then the professionals at the table would discuss his education. She didn't realize that she had the right to contribute to the discussion and express her opinion. "They decided. I agreed," she says. When Jacob, who has autism, was ready to go to middle school, April had ideas about what he needed, but she didn't know how to ask. Someone at the local Urban League told her about The Advocacy Center's Independent Parent Advocacy Network, a DDPC funded project.

DDPC, having a long-standing goal of ensuring that families are trained and active in special education advocacy, provided \$70,000 per year for a three year period during the mid-1990s to The Advocacy Center, located in Rochester NY, to develop a unique 32 hour course on special education advocacy for parents of children with disabilities. While the DDPC funding ended more than ten years ago, The Advocacy Center continues to conduct Parent Advocacy trainings.

As April tells others, "it was liberating to find out I had rights". The course's session on "developing a vision for your child" was a turning point for April. It forced her to think about the future and to commit to taking a more proactive role in planning for Jacob. April enjoyed passing on the information and confidence she had gained to other parents. She began working as a Parent Resource Specialist for The Advocacy Center, reaching out to parents in the city of Rochester.

April credits The Advocacy Center's lay advocacy classes with helping her to build the knowledge and skills to advocate effectively for her son and help other parents as well. She is one of 695 parents from thirteen counties who have participated in the program. As a group, they have assisted thousands of other families with special education advocacy.



April Dixon

- **Direct Support Professional Alliance of New York State
(DSPANYS)
Adult Issues Committee (AIC)**

Direct Support Professionals are accountable for the health, safety, well-being and community inclusion of the people they serve and are the cornerstone of a community-based and person-centered service delivery system.

In 2009, the DDPC sought to develop a sustainable NYS chapter of the National Alliance of Direct Support Professionals (NADSP). Modest seed funding of \$44,000 has allowed the new organization, the Direct Support Professional Alliance of NYS (DSPANYS), to achieve self-sufficiency and sustainability. The heart of the DSPANYS mission is improving the quality of human services in NYS and supporting persons who provide direct supports and services to individuals with disabilities by: promoting the profession of direct support through adherence to a national code of ethics; supporting a national, voluntary, competency-based credentialing process; offering increased access to quality educational and training opportunities; advocating for compensation that is commensurate with the roles and responsibilities of direct support professionals; advocating on local and systems levels for reforms which promote consistency in service delivery by a stable, qualified direct support workforce; and promoting cultures that value the dignity of individuals with disabilities and the importance of the people who directly support them in achieving their life goals.

DSPANYS has worked intensively to develop its professional policies, procedures and public face. The establishment of the NYS chapter was followed by adoption of their organizational by-laws, articles of incorporation, vision and mission statements, and board selection. DSPANYS has conducted six regional DSP conference open forums and has established a presence and voice at the national level through representation on the NADSP Board of Directors. A scholarship program for DSPs has been implemented to offset costs associated with pursuing credentialing through NADSP. They have developed a website and a monthly publication that is disseminated to service provider agencies and policy makers in New York State. More significant is the impact this project has had on DSP interest and involvement. In less than one year, DSPANYS has enrolled over 1,000 voting members, exceeding their target of 300 for this project, as well as 27 supporting and affiliate organizations. Their 501 (c)(6) status allows the organization to receive their income from dues paid by their members. Thus, annual membership dues will enable this fledgling organization to achieve self-sufficiency and sustainability beyond DDPC funding.

The success of DSPANYS project reflects the NYS DDPC's commitment to individuals with developmental disabilities by demonstrating a plan of action that assists the men and women who directly support them. In the words of its founding members, who are Direct Support Professionals from across New York State, DSPANYS...

“envisions a society that recognizes and respects the abilities and value of individuals with disabilities and the people who provide direct supports and services to them.”

• Addressing Transportation Barriers to Employment

Adult Issues Committee (AIC)

The *Transportation and Employment* initiative was intended to address the transportation and employment goals and objectives of the DDPC State Plan.

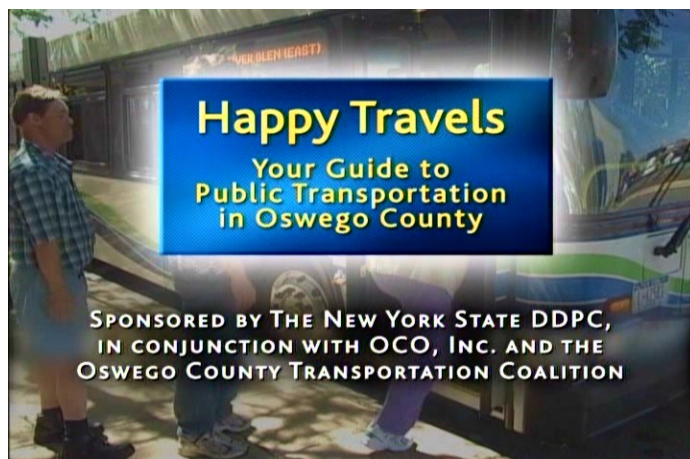
In 2005, Congress enacted the Safe Accountable Flexible Efficient Transportation Equity Act: A Legacy for Users (SAFETEA-LU). This law requires the development of locally coordinated human services transportation plans. It is a vitally important effort in terms of job creation and economic competitiveness, as well as an opportunity to help turn around today's challenging unemployment trends.

In 2007-2009, the NYS DDPC funded diverse approaches to the coordination of transportation and employment for people with developmental disabilities. A major goal was to link people's access to employers, the community, local One Stop Employment Centers and other essential services and supports.

The DDPC funded the Oswego County Opportunities, Inc. (OCO), a nonprofit, human services agency, who partnered with the Oswego County Transportation Coalition to establish *Happy Travels*, a travel training program that includes a train-the-trainer module to develop trainers who can deliver this training within their own communities.

The project has also established a countywide color coded bus schedule system to facilitate ridership. A website and training materials have been developed to help provide greater access to public transportation. The website, www.forthibus.org, provides details on routes and other information about using the public transportation system in Oswego County. The *Happy Travels* training materials include a presentation on

how to use bus services, a reference guide, an informational video giving an overview of using public transportation, and more. OCO has received \$22,000 in additional outside support for this program and continues to make the training available today.



• Inclusive Recreation Resource Center (IRRC)

Systems Coordination Community Education Committee (SCCE)

Several years ago, the NYSDDPC formed a workgroup to examine ways of improving community-based, recreation and leisure opportunities for individuals with developmental disabilities and their families. Numerous workgroup members expressed their frustration with the application understanding of the terms “accessible” and “inclusive” in the promotional materials for recreation and leisure sites. Many of these people had travelled to different areas of the State for vacation (or to participate in a specific-activity) only to find that they were neither accessible nor inclusive.

In 2007, the NYSDDPC established the New York State Inclusive Recreation Resource Center (IRRC) at SUNY Cortland. The intent of the IRRC was to improve the quality and specificity of accessibility assessments and promote the availability of truly-inclusive recreational opportunities to individuals with developmental disabilities and their families. The IRRC work continues and contains the following services:

- **Accessibility Surveys** - a user-friendly tool, the Inclusivity Assessment Tool to help programs and facilities assess both physical accessibility and programmatic inclusion.
- **Online Database for Inclusive Recreation** - an extensive online recreation and leisure database containing information about each site, detailed information about its accessibility and an assessment of the inclusiveness of the program.
- **Training** - Inclusion U is a one-day workshop that certifies Inclusivity Assessors who then are able to complete accessibility surveys and submit the results to the NYS IRRC to be included in the online database for inclusive recreation.
- **Recreation Referral Service** - assistance to participants with disabilities in identifying their recreation interests and goals, exploring and choosing community recreation resources, and working with identified programs, areas, or services on full inclusion. This service is available on a Statewide basis.

Since its inception, the IRRC has gained support and recognition at both the State and federal level. Within NYS, they have presented the Inclusion U training (and other project related materials) at annual conferences of the NYS Recreation and Park Society, the NYS Therapeutic Recreation ASSN., the NYS Outdoor Educators' ASSN., the NYS Disability Advocacy ASSN., the Self-Advocacy ASSN. of NY and the NYS Rehabilitation ASSN. They have also presented at the National Institute of Recreation Inclusion in Portland, Oregon in 2008 and San Antonio, Texas in 2009, at the National Recreation and Parks ASSN.'s Mid-West Conference in Nebraska and at the New Jersey Commission on Recreation for Individuals with Disabilities.

• Congregational Inclusion

Systems Coordination Community Education Committee (SCCE)

Five years ago, we entered into discussion with the Central New York Regional office of the New York State Office for People with Developmental Disabilities (OPWDD) on the topic of developing a more individualized and specific means of determining the spiritual development/ congregational inclusion preference of individuals with developmental disabilities. A project evolved which started with a series of exploratory questions on religious and spiritual involvement and desires asked during the development of the Individualized Service Plan (ISP). If individuals indicated a preference or desires to pursue a spiritual or congregation path, it was included in the ISP which is the guiding document used to plan the services and supports received by the individual.

The Spirit Project, a collaborative effort of the DDPC and OPWDD, was piloted to 50 individuals with developmental disabilities who expressed a desire to begin to participate (or participate more fully) in a congregation or spiritual endeavor. The project documented the obstacles, successes and other considerations faced by the individual, the service delivery system and congregations in fulfilling the expressed desires in the ISP. A variety of tools and resources were developed to assist at each stage of the process. These tools and resources are included in a publication called the *Spiritual Handbook*.

Marje's story illustrates the work of this project. Marje lives in a community residence in Manlius, NY. She used to attend church services on a weekly basis with her legal guardian, Mary Marchica. Mary moved out of the area and Marje greatly missed the weekly congregational experience. During the review of her ISP, she indicated a desire to again be part of a congregation. Rather than taking her and her house mates in a van to an area congregation, Marje's house manager (with assistance from Spirit Project coordinator Margot Wibbe) facilitated a visit for Marje to attend the Eastern Hills Bible Church. The church identified a congregation member to serve as a spiritual partner. The Spiritual Partner (SP) is a very important position in the Spirit Project. Marje's SP had no experience with people with developmental disabilities and was hesitant to take on this responsibility. She was very open in explaining this concern. She is equally willing to share how tremendous the experience has been for her and the congregation.



There is a tremendous difference in people's attitudes and perceptions when they view people with disabilities as accepted members of a community. Marje has very quickly become a member of the Eastern Hills Bible Church congregation and, therefore, has taken on a greater and more meaningful role in the Manlius community.

Left to Right...Jim Huben (NYS DDPC), Margot Wibbe (Spirit Project Coordinator), Delphine Carradino (House Manager), Marjory Jennings (Project Participant), Marilyn Barilla (Spiritual Partner), Mary Marchica (Legal Guardian), Rev. Catherine Patterson (OPWDD Faith Program Coordinator).



Great Seal of the State of New York

**New York State
Developmental Disabilities
Planning Council**

2010 Annual Report

**The 4th Year
Of The 2007-2011 Five Year State Plan**

A Sampling of...

Goal Achievements

by

Area of Emphasis

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:

In 2010, the DDPC continued to work toward reducing the unemployment rate and improving the relative employment/unemployment standing of adults with developmental disabilities when compared to the general public. The Council undertook several projects in order to meet this goal.

The Peer Mentoring and Employment grant assisted over 260 individuals in gaining employment and helped to enroll individuals in One-Stop employment centers. VESID also added over \$1 million in peer-based services to contracts.

Project SEARCH is a program that helps young adults with developmental disabilities obtain employment by giving them the skills necessary to be successful in their new job through a hands-on training approach. In 2010 the DDPC worked with Project SEARCH and Project NOW to create employer based training opportunities. The business immersion model with the University of Rochester Medical Center will be implemented in a downstate demonstration in 2011.

The DDPC also participated in the Most Integrated Setting Coordinating Council (MISCC) Employment Committee which is focusing on 5 areas: increasing access to employment services; data and funding analysis; work incentives planning; employer focused strategies, and public sector employment. The DDPC will work to support OPWDD in their Employment First platform.

Children's Services

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

Goal Achievement:

In 2010, the DDPC worked to increase programmatic responsiveness and inclusion of children with developmental disabilities in education, early intervention, and child care programs. Several projects were undertaken in order to achieve this goal.

The Post-Secondary Inclusion project was a collaboration between the DDPC and the University of Rochester. The Council provided assistance to the University of Rochester as they applied for and received an ADD planning grant to facilitate increased dialogue about post-secondary inclusion. Five regional sessions were conducted along with an Inclusion Institute. In 2011, the University of Rochester will establish a statewide learning community on post-secondary inclusive practices.

The Special Education Taskforce & Inclusion Conference promoted advocacy, mentoring, training & collaboration in Upstate NY. The Taskforce addressed the lack of trained special education advocates by hosting training & mentor meetings. Over 500 individuals attended task force meetings/activities in 2010.

The DDPC's involvement with the New York State Afterschool Network (NYSAN) has resulted in two specific improvements in afterschool policy. One improvement includes a focus on afterschool activities and summer programs to help ease high school drop-out rates. The second improvement involved the DDPC providing information on inclusion to NYSAN which was then used to revise the tool used by NYSAN to assess their programs.

The DDPC continued to work on Foster Care and Adoptive Supports. The DDPC partnered with the NYS Citizens' Coalition for Children (NYSCCC) Adoption and their Foster Care Support Project. The overall goal of the project was to create sustainable support systems for foster, adoptive, and kinship families parenting children with developmental disabilities. The Council also supported the New Alternatives for Children Family Forum which succeeded in providing training to foster and adoptive families and agency staff as well supporting the development of parent support groups and providing referral information to community resources.

Health

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

Goal Achievement:

In 2010, The DDPC engaged in several projects to advance the health agenda of individuals with developmental disabilities. The Nurse Training on Developmental Disabilities and Aging provided training to over 800 health care and direct care professionals. In 2011, the focus will be on particular medical issues such as diabetes and autism spectrum disorders (ASD).

The Telemedicine project evaluation was undertaken by the SUNY School of Public Health with results forthcoming to OPWDD and NYSOFA. Over 30 people in over 15 locations received benefits from this project.

The Parent Partners in Health Education project sought to help medical residents gain a greater understanding of disability related issues through building partnerships with parents and the community. The project was successfully implemented at the Elmhurst Hospital Center's pediatric residency program, the New York Medical College Department of Pediatrics, the Institute for Urban Family Health Inc. and the South Nassau Communities Hospital's family residence program. In 2010, 51 individuals benefitted from the training of 189 people including health care providers and family members.

In 2010, the DDPC supported Fetal Alcohol Syndrome Disease (FASD) Prevention by partnering with The American Congress of Obstetricians (ACOG) to implement a statewide public awareness campaign. A prevention handbook entitled "Pregnant? Think, Don't Drink" was developed and distributed to over 110,000 people. The Learning Disability Association (LDA) also has 2 grants in place which has trained over 170 providers and provided over 400 participants with continuing education units on FASD prevention.

The Healthcare Transition project provided support and training to caregivers to assist youth with developmental disabilities as they transition from pediatric to adult healthcare. In 2010, SUNY Upstate's Institute for Training on Health Care Transitioning has trained nearly 2,000 health care and disability providers and individuals with developmental disabilities and their families.

Housing

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

Goal Achievement:

In 2010, the DDPC worked to increase the housing and support options available to adults with developmental disabilities. Several projects were undertaken by the Council to achieve this goal.

Grant activity under the Nursing Home Waiver and Money Follows the Person resulted in over 400 people receiving waiver support with over 90 transitioning from a nursing home setting.

The NYS Housing Registry is listing close to 1,000 landlords in their online database and receives over 64,000 searches annually. The registry helps individuals with disabilities locate accessible and affordable housing in the geographic location of their choosing. More information on the registry can be found at <http://www.nyhousingsearch.gov>.

The DDPC provides continued support to the Cash Coalition's work which promotes strategies for assets development and retention. In 2010, they returned over \$12 million in assets to the Capital District.

Shared Living is currently in Phase II and will address barriers to implementing shared living strategies and facilitate a statewide community of practice.

The Access to Homes project provides over 100 households annually with environmental modifications that allow people to stay in their homes.

Transportation

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

Goal Achievement:

In 2010, the DDPC worked to decrease transportation-related barriers to participation in employment and community life. The DDPC provided policy advice on transportation accessibility and availability to the MISCC Transportation Committee.

The MISCC Transportation Committee supported multiple interagency efforts to improve transportation for individuals with disabilities in 2010. One of these efforts included the DDPC working with the Department of Transportation to address barriers to improved public and para-transit (flexible transportation). This particular effort also focuses on the concept of county/regionally based mobility managers.

Quality Assurance - Protective/Preventive Services

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

Goal Achievement:

In 2010, the DDPC worked to increase the number of children and adults with developmental disabilities who live in permanent family situations. The Council supported several projects in this area.

An addiction treatment project aimed at assisting individuals with developmental disabilities is in progress. In 2010, a curriculum was developed and provided to OASAS Addiction Treatment Center staff. This project is a collaboration with the NYC Department of Health and Mental Hygiene, the Office of Alcoholism and Substance Abuse Services (OASAS), and the NYS Office for People with Developmental Disabilities (OPWDD).

DDPC distributed the ESCAPE abuse prevention curriculum throughout 2010 DDPC continues to meet the demand from organizations using this abuse prevention curriculum. ESCAPE stands for Effective Strategy-based Curriculum for Abuse Prevention and Empowerment.

The NYS Education Department (SED) has established the Literacy Zone program to ensure individuals have an equal opportunity to learn literacy skills. The DDPC will demonstrate ways that Literacy Zones can effectively assist individuals and families with developmental disabilities in the coming year.

The DDPC supported two initiatives on Foster Care/Adoptive Supports. The NYS Citizens' Coalition for Children (NYSCCC) Adoption and Foster Care Support Project. The overall goal was to create sustainable support systems for foster, adoptive, and kinship families parenting children with developmental disabilities.

The second initiative, New Alternatives for Children Family Forum, succeeded in providing training for foster and adoptive families on topics relevant to foster care, adoption, and parenting children with developmental disabilities. It also provided training for agency staff. In 2010, the DDPC also supported the First Responders project. The project will develop specialized disability awareness and training curriculum for first responders including Fire, Police, other Law Enforcement, and EMT and will implement statewide training which covers the spectrum of developmental disabilities.

Quality Assurance - Advocacy and Leadership

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

Goal Achievement:

In 2010, DDPC worked to increase Advocacy and Leadership skills for individuals with disabilities throughout New York State through multiple projects. One such project was the NYS Disabilities Advocacy Association and Network (NYSDAAN) which made considerable progress to establish a statewide disability advocacy network and achieve a statewide presence and reputation as knowledgeable and well-connected in all areas of disability advocacy, services and supports; and to become a strong partner and leader in systems advocacy to impact positive changes in public policy for people with disabilities and their families. NYSDAAN activities benefitted 280 people (30 with DD, 50 family members, and 200 providers), 229 people were trained on disability topics, 89 people were active in system advocacy, and 70 people were active in advocacy and self-determination.

Partners in Policymaking (PIP) is an example of a successful DDPC partnership aimed at ensuring that individuals with disabilities are active in advocacy efforts. In 2010, PIP graduates worked to develop a network, and 65 graduates have registered on a website developed for this purpose. The DDPC has placed a stronger emphasis on maintaining contact with our Partners graduates. Through a grant initiated with Cornell University and The Advocacy Center, Partners have to maintain their graduate status through a Continuing Education Program (CEP).

The Special Education Taskforce addressed the lack of trained special education advocates by hosting training and mentor meetings in Upstate New York. As of 2010, 260 people were active in system advocacy regarding inclusive education, and 140 people were trained in inclusive education.

Quality Assurance - Workforce

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

Goal Achievement:

The DDPC continues to be committed to increasing the quantity and quality of individuals involved in the developmental disabilities workforce. In 2010, the Council supported several projects in this area.

The Everyday Heroes program, which is designed to highlight the remarkable impact direct support professionals have on the lives of individuals with disabilities, helped approximately 100 direct support professionals develop leadership and inclusion skills.

In 2010, work continued on the OPWDD Direct Support Professionals Advisory Board which is focused on issues related to the workforce. Several policies and approaches were revised in 2010. The Advisory Board supported more than 7 initiatives aimed at improving the quality of and sustainability of direct care staff in both state and voluntary workforce sectors. While progress was made this year, work will continue on in 2011.

The DDPC also funded a Nurses Training initiative. To date, over 600 nurses have been trained with new programs in Pharmacology and Geriatrics.

Quality Assurance - Self-Determination

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

Goal Achievement:

The DDPC is committed to increasing service system reliance on self-determination processes and person centered planning. In 2010, several projects were undertaken to achieve this goal.

Two initiatives included Person Centered Planning in State Prisons (Phase 2) and Person Centered Planning in the Foster Care System. Both activities are currently developing RFP's with several partner agencies.

The DDPC also supported a Self-Determination project with Self-Advocacy of New York State (SANYS) and OPWDD. SANYS was able to expand trainings entitled "We Have Choices" and "Beyond Choices." SANYS also continued the Self-Determination Think Tank and support to self-advocate leaders participating in promoting self-determination. The DDPC was able to provide OPWDD with funding to further construct infrastructure at the DSO level.

The Learning Institute with NYSACRA project provided training and technical support on individualized supports to 11 agencies from the Taconic and Hudson DSO's. The DDPC funded the Nursing Home Waiver & Money Follows the Person which provided over 400 people with waiver services and allowed over 90 people to transition from nursing homes. The DDPC specifically provided policy advice and guidance on program procedures, policy, regulations, and quality assurance.

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:

In 2010, the DDPC worked to increase community capacity to include and serve children and adults with developmental disabilities from under-served populations. Several initiatives were undertaken in this area.

The DDPC worked on the development of the Direct Support Professionals Alliance of New York State (DSPANYS), which is a project undertaken by the DDPC to establish a NYS chapter of the National Alliance of Direct Support Professionals. The idea behind DSPANYS is that by supporting direct support professionals one can improve the experience of the individuals they serve. To date, they have over 1,000 members.

The Addiction Treatment program was established to bridge treatment systems between OPWDD and OASAS in New York City. This project provides enhanced treatment methods for individuals with developmental disabilities who have multiple disabilities.

The Inmate-to-Citizen Project moved into Phase 2 in 2010. The project utilizes person centered principles and infuses them with the pre-release planning of inmates with development disabilities. Phase 2 will create a more appropriate system to support these individuals upon their release back into the community. To date, 15 inmates have been released from state prisons in the New York City region.

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 2010, the DDPC worked to expand the ability for individuals with developmental disabilities to participate in their communities. The Council took on several projects; one such included the Congregational Inclusion Project. This project was meant to allow individuals to worship or practice their religious beliefs in the institution of their choosing. To date, 48 individuals with developmental disabilities, their families, friends, and direct support personnel were participating in congregations of their choice.

The DDPC supported an Inclusive Recreation Grant with the State University of New York (SUNY) Cortland allowed 268 individuals to attend Inclusion U. in 2010. This project has moved into a piloting phase. Both Congregational Inclusion and Inclusive Recreation have been successful in incorporating the work into the normal administration of direct support personnel. NYS Office For People With Developmental Disabilities (OPWDD) and other state agencies have also used the trainings developed through the projects to train their own personnel.

In order to provide greater awareness and training on assistive technology, the DDPC supported an Interagency Partnership on Assistive Technology initiative. This project partnered the NYS Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD) with the Department of Labor Disability Program and provided them with training about the needs for increased awareness and information on assistive technology. A series of articles were published on assistive technology and the role of interagency partnership.

Best Buddies Rural Expansion provided social opportunities for students with intellectual disabilities while creating a new generation of advocates for people with developmental disabilities. In 2010, 12 chapters in rural communities were created serving 32 students with developmental disabilities.

The Telemedicine project helped engage individuals and families in using telemedicine approaches to address health concerns. The project assisted 23 people in 10 locations across the state.

Two ongoing projects in their initial phases include Aging in Community and Family Caregiver Council and Kin Care Coalition. The Aging in Community project will work with OPWDD and NYS Office for the Aging (SOFA) in disseminating training materials and determining how and by whom they should be used. The Family Caregiver Council and Kin Care Coalition will engage with agencies to infuse caregiving approaches and strategies for individuals with developmental disabilities into statewide policy and practice.



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 Andrew M. Cuomo. 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
99 Washington Avenue - 12th Floor - Suite 1230
Albany, NY 12210
518-486-7505

- or -

Email: ddpc@ddpc.ny.gov
- or, available online at -
Website: www.ddpc.ny.gov



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)

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.

DDPC Grantees in 2010

- **AIM Independent Living Center**
- **American Congress of Obstetricians and Gynecologists**
- **Allegany Arc, Wellsville (Allegany County)**
- **ARISE Child & Family Services**
- **Best Buddies New York, Inc.**
- **Center for Disability Services**
- **Consortium on Innovative Practices**
- **Cornell University**
- **Elmhurst Hospital Center**
- **Health Research, Inc. (HRI) / Council on Graduate Medical Education**
- **Institute for Urban Family Health, Inc.**
- **Learning Disabilities Association of New York State**
- **New York City Department of Health & Mental Hygiene**
- **New York Medical College**
- **Niagara University**
- **NYS Association of Community and Residential Agencies (NYSACRA)**
- **NYS Office For People With Developmental Disabilities**
- **Self Advocates Association of New York State**
- **South Nassau Communities Hospital**
- **St. Mary's Hospital for Children**
- **SUNY Cortland**
- **SUNY Upstate Medical University**
- **Support Center for Non-Profit Management**
- **United Cerebral Palsy of New York City**
- **University of Rochester, Institute for Innovative Transition**



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.

NYS DDPC GENERAL QUESTIONNAIRE

NAME: _____

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

99 Washington Avenue - 12th Floor - Suite 1230 - Albany, NY 12210

1-800-395-3372

Patricia Edelstein, *Chairperson*

Sheila M. Carey, *Executive Director*

Rose Marie Toscano, *Vice-Chair*



Great Seal of the State of New York

**New York State
Developmental Disabilities
Planning Council**

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