



**New York State
Developmental Disabilities
Planning Council**

***Project
Summaries***

2008 - 2009

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, and 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.

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Consumer Caucus Chairperson

Sheila M. Carey

Executive Director

Adult Issues Committee

For more information contact:

Nick Rose, Program Planner
518-486-7505

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.rti.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 NYS 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/> . More information on the Nursing Home waiver is available from the NYS Department of Health and can be found [here](#).

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/learnnet/>. 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 (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 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 MTP, 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 intention 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 community “pay it forward” projects. All projects have committed to disseminating their leadership curricula and approaches to self-advocacy and community engagement.

Children's Issues Committee

For more information contact:

Robin Worobey, Program Planner
518-486-7505

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 State-wide 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, a toolkit, and an inter-active 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 the process of 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 organizations 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 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.

Systems Coordination & Community Education Committee

For more information contact:

Jim Huben, Program Planner
518-486-7505

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 more of 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 (SANYSS) 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 over 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 Corrections (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 (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 con-

nected life. Spiritual connection plays a major role for 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, 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 OMRDD's Taskforce on Special Dentistry, the DDPC has funded two (2) 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 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 ensur-

ing 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 to be recreation resources for people with disabilities in their region. A quarterly newsletter is being produced as well as a website and database of recreational assessed sites.