



Great Seal of the State of New York

State Plan

2012-2016

New York State Developmental Disabilities Planning Council

Sheila M. Carey
Executive Director

Patricia Edelstein
Chairperson

Rose Marie Toscano
Vice-Chairperson

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

A message from the...

Chairperson and Executive Director
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 Council's State Plan for (FFY's) 2012-2016, a plan that will bring us to the Council's 45th anniversary in 2016.

In the 1970 reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act, Congress recognized the need for, and value of, strengthening State efforts to coordinate and integrate services for individuals with developmental disabilities. As a result, Congress established and authorized funding for State Developmental Disabilities Councils (DD Councils) in each state. The purpose of Developmental Disabilities Councils was, and continues to advise governors and State agencies on the use of available and potential resources to meet the needs of individuals with developmental disabilities, to help people to live self directed lives, and to make sure individuals are involved in the decision making that affects their lives.

The emphasis of the DD Councils, working with stakeholders, is to increase the independence, productivity, inclusion and integration into the community of people with developmental disabilities, through a variety of systemic change, capacity building, and advocacy activities on their behalf, including development of a State Plan which lays out activities for demonstrating new approaches to enhance lives; training activities; supporting communities to respond positively; educating the public about their abilities, preferences, and needs; providing information to policy-makers to increase their opportunities; and eliminating barriers.

The DDPC looks to all New Yorkers with developmental disabilities, and their families, to assist us in bringing the goals and objectives of the 2012-2016 State Plan to fruition by partnering with the DDPC. We also look forward to receiving concepts that you may have that will help us in achieving the goals, objectives, concepts that may go beyond the stated goals and objectives.

We thank you for all that you did in assisting the DDPC fulfill the goals and objectives of our previous State Plan and look forward to your continued assistance and support.

Sincerely yours,



Patricia Edelstein

DDPC Chairperson



Sheila M. Carey

DDPC Executive Director

2012-2016
State Plan

of the

New York State
Developmental Disabilities
Planning Council

Patricia Edelstein
Chairperson

Sheila M. Carey
Executive Director

Submitted to:

Administration on Developmental Disabilities

August, 2011

Plan Development Oversight Team Members

Ramon Aldecoa

Self-Advocacy Association of NYS

Michelle Appleby

NYS DDPC Member

Patricia Edelstein

NYS DDPC Member

Virginia M. Ellis

NYS DDPC Member

Janice A. Fitzgerald

Parent to Parent of NYS

Dan Flanigan

Self-Advocacy Association of NYS

Renee Hallock

NYS Office of Children and Family Services

Rosemary Lamb

Commission on Quality of Care and Advocacy for Persons with Disabilities

Aldea LaParr

NYS DDPC Member

Barbara Levitz

NYS DDPC Member

Wendy Orzel

NYS DDPC Member

Susan Richardson

NYS Office for People with Developmental Disabilities

Ann Scherff

NYS DDPC Member

Kathy Serino Duffy

Commission on Quality of Care and Advocacy for Persons with Disabilities

Dora Lee Stanley

Adult Career and Continuing Education Services—Vocational Rehabilitation

Plan Development Oversight Team Members

(Continued...)

Stephen B. Sulkes, M.D.

Strong Center for Developmental Disabilities UCEDD

Robin Hickey

NYS DDPC Staff

Nicholas Hobson

NYS DDPC Staff

James Huben

NYS DDPC Staff

Karen Jackuback

NYS DDPC Staff

Kathy Leggiero

NYS DDPC Staff

Anna Lobosco

NYS DDPC Staff

John R. McDonald

NYS DDPC Staff

Kerry Wiley

NYS DDPC Staff

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PREFACE

This State Plan represents a contract between New York State and the federal government for receipt of funds under the 2000 amendments to the Developmental Disabilities Assistance and Bill of Rights Act. In order to receive funds under this legislation, the State must submit a State Plan which will be used as a basis for participation in programs and activities under Title I, Part B of the Act. This State Plan is effective from October 1, 2011 to September 30th, 2016 and covers federal fiscal years 2012, 2013, 2014, 2015 and 2016.

The purpose of the Developmental Disabilities Assistance and Bill of Rights Act is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports and other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all facets of community life through culturally competent programs. This legislation is intended to assist customers of the developmental disabilities service system in becoming fully involved in the design, implementation, evaluation, and quality assurance aspects of the programs that serve their needs. A primary avenue for attaining this goal is support for systematic change, capacity building, and advocacy activities undertaken by the New York State Developmental Disabilities Planning Council (DDPC).

Thus, the purpose of the 2012-2016 New York State Developmental Disabilities Planning Council State Plan is to:

- act in accordance with the Developmental Disabilities Assistance and Bill of Rights Act;
- advise the citizens of New York State about the priorities, goals, objectives and activities of the Developmental Disabilities Planning Council (DDPC) so that they can participate in the planning process in a knowledgeable manner; and
- provide the Administration on Developmental Disabilities and the Secretary of Health and Human Services and New York State government officials with reliable and useful information for the development and revision of national and state policies addressing the needs of children and adults with developmental disabilities and their families.

INTRODUCTION

The New York State Developmental Disabilities Planning Council (DDPC) developed this five year State Plan based on its 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. Thus, our activities and resources are directed toward affecting change in the way the community and the service system responds and relates to individuals with developmental disabilities and their families.

The process for selecting state plan priorities, goals, and objectives followed the planning requirements as written in federal law. In compliance with these requirements, the DDPC:

- undertook a review and assessment of activities undertaken in previous years;
- initiated a comprehensive review and analysis of the current service system for individuals with developmental disabilities and their families, including other related federally-supported programs in the State; and
- provided opportunities for input about the policy direction and focus of the DDPC activities to individuals with developmental disabilities, parents and family members, advocates, providers and other interested citizens and groups.

Developing this plan required some difficult choices about what could be included. The DDPC decided to focus on areas of most pressing need, endeavors with the greatest potential for affecting desired change, arenas where there is a defined role for DDPC which is different from that of other entities, and concerns identified in the Developmental Disabilities Assistance and Bill of Rights Act and its amendments. Generally, these choices were consistent with the information that was presented to us through DDPC information gathering activities.

Based on the above considerations, the 2012-2016 DDPC State Plan has been designed to address the critical, unresolved issues currently confronting individuals with developmental disabilities and their families.

Developmental Disabilities Planning Council

The New York State Developmental Disabilities Planning Council (DDPC) is a planning and advocacy body established under both federal and state law. Under the Federal Developmental Disabilities and Bill of Rights Act of 1975 (as amended in 1978, 1984, 1987, 1990, 1994, 1996, and 2000) and New York State Executive Law, Section 450, (as in Chapter 588 of the New York State Laws of 1981), the DDPC has the responsibility to plan and coordinate resources so as to protect the legal, civil and service rights of persons with developmental disabilities.

General Statement of Philosophy

The New York State Developmental Disabilities Planning Council (DDPC) recognizes that disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities, including individuals with severe disabilities, to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural and educational mainstream of American society. This is based on the belief that all people, including individuals with severe developmental disabilities, are created equal and are entitled to have their legal, civil and human rights respected and protected.

Mission Statement

The New York State Developmental Disabilities Planning Council (DDPC), in partnership with individuals with developmental disabilities, their families and communities, provides leadership by promoting public policies, plans, and practices that:

- *affirm dignity, value and worth;*
- *support full participation in society;*
- *uphold equality and self-determination; and*
- *promote access to research and information needed for informed decision making for all individuals with developmental disabilities and their families.*

Developmental Disabilities Planning Council

Organization

The DDPC is currently composed of 29 members who have been appointed by the Governor of New York State. Federal law requires that at least 60 percent of that membership be persons with developmental disabilities, parents/guardians of such persons, or immediate relatives/guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves. Other required members include representatives from several state agencies that administer federal disability-related programs, University Centers for Excellence, the Protection and Advocacy Agency (P&A), local agencies, non-governmental agencies and private not-for-profit groups concerned with services to persons with developmental disabilities in New York State.

The Chairperson of the DDPC is appointed by the Governor from the membership.

The DDPC Chairperson and Executive Director work with the Governor's Office to ensure that federal membership requirements have been met. Individuals interested in serving as a member of the DDPC are encouraged to contact the DDPC using the form at the end of this document.

The DDPC has a full-time staff solely responsible for assisting the DDPC in carrying out its duties and functions under the direction of the Executive Director. A listing of the members of the DDPC and a listing of DDPC staff can be found on pages 5-7.

As an agency established in the Executive Department of New York State government, the DDPC carries out its role independent of other state agencies. It works in consultation with the New York State Office for People with Developmental Disabilities (OPWDD), and other relevant state agencies to ensure interagency coordination of activities and to promote systemic change.

The current DDPC Chairperson and Executive Director are:

Patricia Edelstein, Chairperson

NYS Developmental Disabilities Planning Council
99 Washington Avenue / 12th Floor - Suite 1230 / Albany, NY 12210
Telephone: (518) 486-7505 / 1-800-395-3372

Sheila M. Carey, Executive Director

NYS Developmental Disabilities Planning Council
99 Washington Avenue / 12th Floor - Suite 1230 / Albany, NY 12210
Telephone: (518) 486-7505 / 1-800-395-3372

COUNCIL MEMBERSHIP

~ Consumer Members ~

Michelle Appleby

Patricia Edelstein, *DDPC Chairperson*

Virginia M. Ellis

Tamelia Laquana Fritz

Shirley Goddard

Kevin Kennedy

Aldea LaParr

Barbara Levitz

Lawrence Lieberman

Wendy P. Orzel

Rain Rippel

Ann L. Scherff

Beatrice Schmidt

Rose Marie Toscano, *DDPC Vice-Chairperson*

Trish Washburn

~ Non-Governmental Agency Member ~

Janice A. Fitzgerald

~ University Centers for Excellence Members ~

Ansley Bacon, Ph.D.

Robert W. Marion, M.D.

Stephen B. Sulkes, M.D.

~ **State Agency Members** ~

Honorable Darryl C. Towns
Commissioner
NYS Division of Housing and Community Renewal

Honorable Elizabeth R. Berlin
Executive Deputy Commissioner
NYS Office of Temporary and Disabilities Assistance

Honorable Brian S. Fisher
Acting Commissioner
NYS Department of Corrections and Community Supervision

Honorable Greg Olsen
Acting Director
NYS Office for the Aging

Honorable Joan McDonald
Commissioner
NYS Department of Transportation

Honorable Courtney Burke
Commissioner
NYS Office for People with Developmental Disabilities

Honorable Dr. John B. King, Jr.
Commissioner
NYS Education Department

Honorable Nirav R. Shah, M.D., M.P.H.
Commissioner
NYS Department of Health

Honorable Roger Bearden
Chairman
NYS Commission on Quality of Care and Advocacy
for Persons with Disabilities

DDPC STAFF

Sheila M. Carey, Executive Director

Nathaniel Douglas, Keyboard Specialist

Isaac Handy, Calculations Clerk II

Robin Hickey, D.D. Program Planner II

James Huben, D.D. Program Planner II

Karen Jackuback, D.D. Program Planner II

Thomas F. Lee, Public Information Officer

Kathy Leggiero, Associate Budget Analyst

Anna F. Lobosco, Ph.D., D.D. Program Specialist IV

Ellen Meyers, Special Assistant

Tom Meyers, Information Technology Specialist II

Marybeth Stoddard, Secretary I

Kerry Wiley, M.S.W., Program Research Specialist II

Internship Program:

The DDPC hires graduate and post-graduate students from the State University of New York at Albany and other local colleges to supplement and assist staff as well as to encourage their entry into the disability field. Current interns are:

Nicole Bak

Nicholas Hobson

John R. McDonald

Ashley Pacelli

PLAN DEVELOPMENT PROCESS

Information Gathering

Developing this plan was a multi-pronged two year process with outreach to relevant stakeholders across New York State. Information was brought back to the DDPC at each stage of the process and used to build and refine the goal and objective statements. The following is the roadmap used in the information gathering process.

- **Background Papers**
- **Review Prior Work of the DDPC Standing Committees and Workgroups for Relevant Findings**
- **Obtain and Review Public Forum Summaries**
 - ◆ New York State Office for People with Developmental Disabilities (OPWDD) Constituent Forums
 - ◆ Most Integrated Setting Coordination Council Forums
 - ◆ OPWDD 5 Year Plan Hearings
 - ◆ Regional Transportation Forums
 - ◆ OASAS Forums on Fetal Alcohol Spectrum Disorder (FASD)
 - ◆ OPWDD Housing Regional Forums
 - ◆ Adult Career and Continuing Education Services—Vocational Rehabilitation (ACCES-VR) Town Hall Meetings
 - ◆ Individuals with Disabilities Education Act (IDEA) Public Meetings
 - ◆ Maternal Child Health Assessment
 - ◆ Self-Advocacy (SANYS) Statewide Conference Focus Groups and Policy Statements
 - ◆ Medicaid Redesign Regional Forums
 - ◆ Shared Living Forums
 - ◆ Individualized Supports Think Tank Deliberations
 - ◆ State Education Department Performance Reports to the Federal Government
- **Review Existing Survey Results**
 - ◆ DDPC Consumer Satisfaction (2007-2009)
 - ◆ National Council on Disability

- ◆ National Core Indicators (NCI)—New York State and National
- ◆ DD Clinician Recruitment/Retention
- ◆ Mental Hygiene Joint Planning Data
- ◆ Others as available

- **Solicitations on Issues**

- ◆ Conferences of Local Mental Hygiene Directors
- ◆ Statewide Provider Organizations, including the Direct Support Professionals Alliance of New York State
- ◆ Real Choice Committees and Workgroups
- ◆ Clinicians
- ◆ Protection and Advocacy Program Case Issue Review
- ◆ Advocacy Organizations, PTICs and Special Education Parent Centers

- **Collaborations**

- ◆ Developmental Disabilities Network and Other State Agency Plans
- ◆ Input from Consumer Groups (i.e., Self Advocacy Association of New York State, Parent to Parent of New York State, Consumer Advisory Committees, Partners in Policymaking, and Sibling Workgroups) and Developmental Disabilities Network Partners (i.e., Protection and Advocacy Board, University Centers for Excellence Consumer Advisory Panels), and many statewide and regional agencies and organizations
- ◆ Relevant workgroups of the Conference of Local Mental Hygiene Directors
- ◆ State Education Department—Race to the Top Initiative
- ◆ Office of Mental Health Children’s Plan and Children’s Subcabinet
- ◆ Congregational/Faith-Based Initiatives
- ◆ CQCAPD Quality Initiative
- ◆ New York State Planning Effort for the Alliance for Full Participation (AFP) Summit
- ◆ Other - as necessary and available

- **Outreach to the DD Community**
- **Individual and Family Survey (Areas of Emphasis - All)**
 - ◆ Paper and web-based option
- **Provider Survey**
 - ◆ Web-Based with Paper Option

Priority Setting

- **External Focus Groups**
 - ◆ Self-Advocacy Association of New York State (SANYS) Conferences (2009, 2010, 2011)
 - ◆ Parent-to-Parent of New York State and Family Support Services (FSS) Regional Conferences
 - ◆ Statewide Organization Conferences
- **Internal Focus Groups**
 - ◆ June 2010 and 2011 DDPC Work Sessions

Public Comment

- **Public Comment Period**
 - ◆ Mail and Web-based Options

The following is a...

Portrait of the

New York State

Service System

for

People with

Developmental Disabilities

EDUCATION / EARLY INTERVENTION

The Council of State Governments cites education as the cornerstone of disability policy advocates and policy-makers. Education issues are often considered important as states are commonly the providers of these services for individuals with, and without, disabilities. Because individuals are most commonly in the educational system for what may be their most formative years (childhood through young-adulthood), considering what the educational system offers, as much as what it does not, is an important consideration for all individuals in the educational system.

National statistics on school-age children and teens with disabilities suggest that many students with disabilities are being served by the same schools that serve students without disabilities. According to the National Center for Education Statistics, in Fall 2007, some 95 percent of 6 to 21-year-old students with disabilities were served in regular schools; 3 percent were served in a separate school for students with disabilities; 1 percent were placed in regular private schools by their parents; and less than 1 percent each were served in one of the following environments: in a separate residential facility, homebound or in a hospital, or in a correctional facility.

According to the New York State Education Department Annual Report, in 2008, the statewide percent of students with disabilities, ages 6-21, served inside regular classrooms 80 percent or more of the school day was 55.4 percent. Inclusion continues to be a focus of work supported by the DDPC and having more than 50% of students with disabilities participating in “typical” classrooms 80% of the school day is a positive achievement to note while working to increase that percentage in coming years.

The 2003 graduation rate for all students in New York State schools was 71% compared to 41.2% of students with disabilities. Graduation rates for students with disabilities increased to 43.6% in cohort year 2004. The increase in graduation rates for students with disabilities rose at nearly the same rate as the total graduation rates for all students in the same year (73.6% of all students in 2004). The New York State Office of Adult Career and Continuing Education Services— Vocational Rehabilitation (ACCES-VR) provided more than 60 schools with funds to implement improvement activities. Many of these improvements were related to improving instruction to individuals with disabilities in those districts

and to increase the number of students with disabilities who graduate.

For the 2009-2010 School year, the New York State Education Department Information and Reporting Service reports 183,578 high school completers and 36,216 non-completers, of which 17,297 completers and 9,528 non-completers were students with disabilities. There is no reliable way to make the distinction between students with disabilities and those with developmental disabilities. Of those students with disabilities:

- 9,300 (54%) received a diploma, 5,566 received an IEP diploma, and 1,924 (1%) entered a GED program;
- 12,807 (56%) went on to some kind of post-secondary program, 445 (1%) to the military, 3,592 (16%) to employment, 979 (4%) to adult services, and 570 (2%) with plans unknown; and
- Graduation statistics from 2009 show that only 1 in 4 students with disabilities graduated from high school in 4 years.

New York State offers unique, but segregated, school environments for individuals with disabilities to attend if they choose. One such example is the New York State School for the Blind (NYSSB) which offers a unique school experience for children that are blind. Evaluation leading to acceptance and attendance to NYSSB are provided at no cost to the families of students through various funding streams including New York State, State Education Department, and the county in which the family of a NYSSB student lives. Similarly, New York State offers a unique school experience for individuals who are deaf—the New York State School for the Deaf (NYSSD). The NYSSD works to provide a foundation of learning that will enable students to become independent, self-respecting and contributing adults in a multi-cultural society. Educational programs provided through NYSSD are offered to youth with disabilities at various stages of development from infancy through high school graduation.

Best Buddies International is a non-profit organization with an active chapter in New York State. Establishment of the New York State Central Office for Best Buddies came through grant assistance from the DDPC, which allowed the Best Buddies program to expand throughout the State. The annual budget for the Best Buddies national program in 2009 was \$22,000,000 through donors, merchandise, fundraising, and government grants. The program aims to benefit individuals with and without disabilities by encouraging connections between school-age individuals with disabilities and their peers without disabilities. According to the Best Buddies NY website, the program reaches around 15,000 people each year with

more than 60 chapters in middle schools, high schools, and colleges throughout New York State.

In 2007, DDPC announced that it would award Best Buddies NY \$100,000 to expand services and the reach of the program for children between ages 9 and 13. These funds would help expand the program to middle schools throughout the state and increase the ability of existing chapters to create meaningful relationships between students with and without disabilities. Because Middle School is generally considered a transitional period for young adolescents, there is often a great deal of social and emotional changes that occur during the Middle School years.

Moving forward, the New York State Education Department (SED) is undertaking a major restructuring of how Special Education and Vocational Rehabilitation (VR) services are managed and administered. Special Education will be relinking within Elementary, Middle and Secondary Education, while VR will be restructured within Adult Career and Continuing Education Services (ACCES-VR) unit combining workforce development, adult literacy, technical and proprietary education and GED. The intent is to align components more consistently with IDEA and the Workforce Investment Act (WIA).

SED has been actively engaged in the Race to the Top competition and in working with OPWDD and the Interagency Task Force on Autism Spectrum Disorders. SED has also expanded an enhanced system of Early Childhood Direction Centers and Special Education Parent Centers intended to promote meaningful parental involvement in local special education programs.

HEALTHCARE

Issues of health are a major focus in policy and services for individuals with disabilities, because good health is one of the factors contributing to quality of life. Many agencies and programs throughout New York State focus on the delivery and quality of health services for individuals with disabilities. The New York State Office for People with Developmental Disabilities (OPWDD), the New York State Department of Health, the New York State Office of Temporary and Disability Assistance, the New York State Education Department, the Office of Mental Health, the New York State Office of Alcohol and Substance Abuse Services (OASAS), and health insurance programs like Child Health Plus are just a few examples of the many agencies/programs dedicated to helping New Yorkers with disabilities access appropriate and affordable health care.

The Behavioral Risk Factor Surveillance Study found the distribution of individuals experiencing a disability, aged 18+, in New York State in 2006 was as follows: 11.6% were aged 18-44; 22.6% were aged 45-64; and 34.7% were aged 65 or older. The same study also asked individuals with, and without, a disability to rate their own health status. Considering individuals with a disability, 40.6% reported their own health as “fair or poor,” 30.0% reported their health as “good,” and 29.4% reported their health as “excellent or very good.” Individuals without disabilities tend to describe their health more positively than individuals with disabilities. 59.1% of individuals without a disability reported their health to be “excellent or very good,” and 30.3% classified their own health as “good,” while only 10.5% of these individuals described their health as “fair or poor.” The differences present in the way these populations describe their own health suggests that individuals with disabilities could benefit from improved health options and services.

There is continued expansion of the Medicaid Buy-In for Working People with Disabilities which now has approximately 7,000+ current enrollees. DOH is planning to implement policy for the Consumer Directed Personal Assistance Services (CDPAS) program which is used by approximately 8,800 persons. There has been some improvement in access to assistive technology through the Money Follows the Person initiative, as well as improved access to durable medical equipment (DME). New York State continues to implement the New York State Connects program at the county level which has created a single point of entry for long-term care with an increasing emphasis on maintaining people in their homes. There is concern for long-term care home-based services based on Medicaid re-

ductions and proposed rate reductions in a system that still has an institutional care bias.

According to the OPWDD 2010/2011 Budget Briefing Booklet, it is estimated that of the 125,000 individuals with developmental disabilities that OPWDD helps support, approximately 21,000 have autism or disabilities within the continuum known as ASD, or Autism Spectrum Disorders. These numbers are similar to those of a 2009 State Autism Profile of New York prepared by Easter Seals, both of which can provide insight into the demographics of individuals with ASD in New York State. The Easter Seals profile states that in 2000, 6,752 or 1.53% of children ages 3-21 who received special education services in New York have autism. In 2007-2008, 17,601 or 3.88% of children with disabilities ages 3-21 who received special education services have autism. While the number of children with disabilities defined as “autism” has increased in recent years, it should be noted that identification methods have changed which may explain a portion of the increases in autism diagnoses. New York State established an Interagency Taskforce on Autism. The taskforce published a report highlighting the opinions of individuals and family members facilitated by Centers for Autism and Related Disabilities (CARDs) throughout the state. The results of this survey were published in January 2010 with the taskforce providing 27 recommendations in five areas of need.

Individuals with disabilities enrolled in Medicare may be eligible to participate in the Medicare drug benefit Part D which makes prescription drugs more affordable for individuals receiving Medicare. In 2008, OPWDD reported that approximately 43,000 people being served through their system were enrolled in Medicare Part D plans.

The New York State Child Health Plus program provides health insurance to children in New York State with no insurance premiums depending on the income of the family applying for coverage. Child Health Plus can also include Dental and Vision coverage for qualified enrollees. OPWDD provided training to 98% of their service coordinators on how to link individuals with disabilities, and their families, to services and supports that they may be eligible for but are not currently receiving.

Nutrition is an important factor in maintaining good health. To ensure individuals being served by OPWDD receive the best possible nutritional assistance, OPWDD cites the Nutrition Care Process which is a dynamic systemic approach to providing high quality nutrition care that was just developed by the American

Dietetic Association for use by dietitians nationwide. The four components of the process are Nutrition Assessment, Nutrition Diagnosis, Nutrition Intervention, and Nutrition Monitoring and Evaluation. Linked closely with dietary issues, OPWDD acknowledges the need to promote exercise and heart-healthy practices. The OPWDD Statewide Comprehensive Plan states that when discussing issues related to health and weight, about a third of respondents (individuals with disabilities) reported that weight was a concern and about three in ten reported that they were not physically active. These responses highlight the need for focus on nutrition and exercise options for individuals with disabilities.

The New York State Office of Alcoholism and Substance Abuse Services (OASAS) provides services to individuals with chemical dependencies and other addictions. One area of focus for OASAS related to developmental disabilities is in raising awareness for Fetal Alcohol Spectrum Disorders (FASD) which consists of an array of potential life-long effects experienced by individuals when alcohol is ingested during pregnancy. The Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA) found that 40,000 babies are born with FASD spectrum conditions in the United States each year. DDPC has worked to increase awareness of FASD by partnering with the American Conference of Obstetricians and Gynecologists (ACOG) to develop video and radio Public Service Announcements (PSA) to educate the public about risks and prevention measures related to FASD. The educational video on FASD (funded by DDPC) is currently running three times a day on the Newborn Channel, which is played in more than 1,000 hospitals throughout the United States—including nearly 80 hospitals in New York State, and reaches more than 2.5 million new mothers every year. The radio PSA is estimated to have reached more than 500,000 people.

With rising Medicaid costs impacting the State, the DDPC (at the request of the OPWDD Commissioner's Task Force on Aging) funded a Telemedicine project aimed to reduce Medicaid costs by providing medical assistance via telephone or video conference. The Telemedicine project puts individuals in direct communication with trained nurses to address minor medical issues to avoid unnecessary visits to the hospital.

The DDPC has made a great impact in connecting physicians to families through the Parent Partners in Health Education (PPHE) initiative. PPHE will be expanded to physician assistants and nursing staff. The DDPC also is making an impact, in New York State and other states as well, by increasing the awareness of Health Care Transition (HCT) for adolescents with disabilities via the establishment of

the New York State Institute for Health Transition Training; and a web based curricula.

In addition, the DDPC remains involved in working with the Rehabilitation Research and Training Institute (RRTI) to train nurses in the DD field. Current topics have included mental health, behavioral issues, diabetes, pharmacology, and telemedicine applications.

EMPLOYMENT

The New York State Education Department recently restructured its services so that the Office of Vocational and Educational Services for Individuals with Disabilities is now the Office of Adult Career and Continuing Education Services—Vocational Rehabilitation (ACCES-VR). ACCES-VR works collaboratively with the Commission for the Blind and Visually Handicapped (CBVH), the Office for People with Developmental Disabilities (OPWDD), and the Office of Mental Health (OMH) to increase the effectiveness and availability of integrated transition employment programs for individuals with developmental disabilities. These efforts are classified in Chapter 515 of the Laws of 1992. ACCES-VR published an annual report on efforts under Chapter 515 in 2008 which states that between April 1, 2007 and March 31, 2008, 24,519 individuals with disabilities participated in supported employment. These individuals with disabilities engaged in supported employment worked an average of 23.44 hours per week. ACCES-VR concluded that at the time of publication “the employment rate of working-age people with disabilities (ages 21-64) is 33.5% as compared to 77.9% for people without disabilities, a gap of 44.4%.” ACCES-VR administers the Ticket to Work and Self-Sufficiency Program which provides access to services and supports needed to attain, maintain, and advance employment. The American Community Survey (ACS) found similar results looking at the employment rate of individuals with disabilities in New York State in 2007. The ACS found that of the 1,402,603 individuals with a disability ages 16-64 “living in the community,” about 463,867 (or 33.1%) were employed.

ACCES-VR counts youth and individuals who have applied for the vocational rehabilitation program prior to age 22 and reports the following for Federal Fiscal Year 2010.

- ACCES-VR had an active caseload of 23,438 youth/young adults; youth and young adults made up 44% of the total active caseload. “Active” refers to individuals eligible for VR services and/or individuals who have an Individualized Plan for Employment (IPE).
- 4,318 youth achieved an employment outcome after receiving VR services. This is an increase for the fourth consecutive year even though the overall number of employment outcomes (for all ages) decreased in recent years.
- The active caseload consisted of 9,816 individuals with ID/DD (18.5% of the active caseload) and 2,184 individuals with ID/DD achieved an employment outcome after receiving VR services under an Individualized Plan for Employment.

These numbers are not limited to only those currently under 22; it includes those applying prior to age 22 and continuing to work with ACCES-VR even if they turn 22 and are now older.

According to the most recent (2008) Survey of Income and Program Participation (SIPP) Census Bureau report:

- 28.4% of non-institutionalized persons ages 21-64 with a developmental disability were employed in the U.S., with median monthly earnings of \$600 (+/- \$201)
- 83.5% of non-institutionalized persons ages 21-64 without any disability were employed in the U.S., with median monthly earnings of \$2,539 (+/- \$24)

This is a 55.1 percentage point gap in employment rates between these two groups.

OPWDD also works to improve the number of work opportunities for individuals with disabilities in New York State. One way OPWDD works to this goal is through the Employment Training Internship Program (ETP) which encourages businesses to hire individuals with disabilities with OPWDD paying the employee's wages for 18 months. As individuals with disabilities are able to make a fair wage for their work, businesses have the opportunity to see how individuals with disabilities can benefit their business. As of 2010, 300 interns are participating or have participated in ETP.

Another program aimed to increase parity in employment for individuals with disabilities is the OPWDD Enhanced Supported Employment pilot. The pilot aims to assist individuals with disabilities in achieving employment through a 5 year plan resulting in 700+ individuals obtaining employment. By mid-2010, 200+ individuals with disabilities have obtained employment through the program.

OPWDD has approximately 9,300 people in employment services with 32,000 people in non-employment day service options. OPWDD seeks to double the number of people in employment services with an immediate goal of increasing their baseline by 15%. Activity specific to school-to-work transitions include:

- There are currently 306 18-22 year olds (of 9,929 individuals of all ages) receiving pre-vocational services and 530 18-22 year olds (of 9,058 individuals of all ages) receiving employment supports.
- In looking at a 10 year period from 2005 to 2014, 901 transitioned or are expected to transition to OPWDD services from a residential school placement with 55% of those individuals transitioning in 2012 and beyond.

In 2011, OPWDD will be implementing a comprehensive Employment First initiative intended to make employment a focus for all people within that system. In addition to an Enhanced Supported Employment initiative that will target 700 new employment opportunities, OPWDD seeks to implement:

- Pathways to Employment to focus on assisting people in non-employment day habilitation to have job development/matching and job coaching supports to move into employment;
- Students Work Too to enable students in their last 2 years of high school be supported in after-school and weekend employment opportunities;
- Community Habilitation to provide individualized supports for community service, volunteerism and other self-directed options (i.e., entrepreneurship) to assist people with community engagement and employment outcomes.

OPWDD is also looking to scale up DDPC transition demonstration grants such as Project Search, community service and post-secondary inclusion for wider availability within the developmental disabilities service system.

One barrier to employment is that many support programs that benefit individuals with disabilities will no longer support individuals if they make more than a certain amount in wages. The New York State Department of Health provides assistance for individuals who lose their Medicaid benefits due to salary. The Medicaid Buy-In Program allows individuals with disabilities earning a salary above program specifications to continue to receive health coverage. To be considered for this program, individuals can earn up to \$55,188 and couples can earn up to \$73,884. Currently there are 7,000+ New York State participants in the Medicaid Buy-in Program including 3,400 individuals with Developmental Disabilities; New York State has had over 12,000 participants since the inception of this program.

HOUSING

Individuals with disabilities in New York State benefit from many housing initiatives designed to increase access to accessible and affordable living arrangements of their choosing. One such program is the New York State Housing Registry. In July 2010, 89,500 units were listed on the registry website with 1,107 owner/landlords/etc., listed as well. In a 12-month period leading to July 2010 the registry was accessed and searched over 249,000 times. Considering the number of listings compared to the volume of site traffic the registry receives, the registry is evolving into a popular destination for housing options/information for individuals with disabilities and landlords. The NYS DDPC has been involved with the registry since 2003 when DDPC established an initiative for a directory listing private and public housing options for individuals with disabilities. While the genesis of this project was with DDPC, the New York State Division of Homes and Community Renewal took over the contract and helped the directory become a useful reference for individuals with disabilities looking for housing options.

The Council of State Governments (CSG) conducted a survey of State Disability Policy in 2010. The report suggests that when individuals with disabilities are unable to find adequate/accessible housing options they may live in places that threaten their well-being; without proper accommodations individuals with disabilities may face a greater risk of injury due to falls than those living in units with adequate features. CSG also suggests that individuals with disabilities living in housing that is not properly outfitted may be more likely to experience isolation and may be less willing to leave the home for fear of injury or the difficulty present in performing activities outside the home. This isolation is the type of result DDPC and many other agencies work to correct through programs, and a mission, focused on inclusion for individuals with disabilities in communities of their choosing.

While residential settings are trending toward more personal, community-based, and accessible environments, there is need to ensure that older buildings are made accessible while newer residences are built with accessibility in mind. Planning for accessibility in new construction will reduce the need for retro-fits at a later date. The Access to Home program provides financial assistance to individuals looking to modify their existing property to be more accessible. By modifying homes/dwellings, individuals are more likely to be able to remain in a residential setting of their own choosing. In 2008, the Access to Homes Program assisted in the modification of 591 units. 2009 saw only 96 units assisted, but because of the

way funds are dispersed, many units will be completed using 2009 funds in 2010 and beyond which will increase this number over time. To date, the total number of units assisted through Access to Homes is near 2,220.

The Office of the New York State Comptroller audited OPWDD residential placements in 2004 finding that, through the NYS-CARES program, 5,075 additional residential options were made available to individuals with developmental disabilities. The goal for this project was to create 4,890 residential options; so the number of options available shows that the program exceeded its goals by about 4%. The “goal” vs. “actual” numbers show that almost all regions served by OPWDD met or exceeded their goals. The three underperforming regions are all located in the New York City and Long Island area of the state (Queens, Long Island, and Metro NY). The Queens location was about 1% below the goal, Long Island was about 8% below the goal, and Metro NY was about 18% below the goal. The concentration of below-goal results being within the New York City and Long Island area suggests there are barriers to the creation of residential placements that may be unique to this geographic location. However, these locations had goals that were often twice that of other regions in the state, so differences between regions may be due to volume; considering the actual number of beds made available, Metro NY and Long Island both created more residential options than neighboring regions (Hudson Valley, Brooklyn, etc.) that had met or exceeded their goals. Looking at these issues regionally, underperforming areas are clustered in highly-populated locations associated with a high cost-of-living.

The New York State 2010-2011 Executive Budget supports the development of about 2,600 new residential opportunities. 510 of these proposed opportunities would be associated with the OPWDD NYS-CARES initiative. While there is an increase in the general number of options, certain housing opportunities for individuals aging out of school and children placements would be delayed until a future date when additional funds are available (this date is not yet determined).

The Department of Housing and Urban Development (HUD) provided OPWDD with \$165,000 to support new and existing housing programs. One such program is the OPWDD Home of Your Own (HOYO) program which began in 1996, under DDPC funding, and is one of the longest tenured housing programs at OPWDD. HOYO provides counseling and services to individuals with disabilities and their families on many aspects of home ownership. By January 2010, there had been \$19.8 million in State of New York Mortgage Agency loans through HOYO and as of Mid-2010, \$1,248,413 in loans through a formal partnership

with USDA Rural Development. Recently, HOYO has been expanded to include eligible parents/legal guardians of individuals with disabilities as well as direct support professionals. Over 300 applications were pending in the HOYO program as of Spring 2010. Additionally, during the first half of 2010, five (5) individuals purchased their first home, and four (4) individuals were in the process of purchasing a home through HOYO. More recently, DDPC played a key role in the HOYO initiative with the Real Choice Systems Transformation Grant which would identify barriers to existing housing resources, expand the existing policy issues group, develop web-based housing information supports, and develop a marketing campaign.

As of 2008, New York State had 10 large residential facilities in operation. According to a University of Minnesota report, the only state to have more large residential facilities in 2008 was Texas with 13. While many programs focus on the avoidance of institutionalization, statistics on these types of living options are still relevant when considering all housing for individuals with disabilities in New York State. According to the Status and Trends Through 2008 report, the total state institution population for New York State in 2008 was 2,119. Nine years prior to 2008, the state institution population in New York State was 8,179. This substantial reduction in the number of individuals with disabilities living in an institutional setting could be attributed to a programmatic focus on community inclusion and ensuring that individuals are able to live in the residential settings of their own choosing. A similar trend can be seen in the average home size that individuals with disabilities are living in currently as opposed to almost 30 years ago. In the late seventies, the majority (21,239 of 26,552) of individuals with an intellectual, or developmental, disability lived in a home setting with 16+ other people, but in 2008, the majority (42,808 of 45,940) of individuals lived in a home setting with fewer than 15 other people. This shift in numbers suggests that as individuals move away from large institutional settings, they are living in smaller settings. In the same 30 year period, the number of individuals with disabilities under the age 21 or younger living in an institutional setting has dropped dramatically; in 1977 36% of individuals in this age-range lived in institutional settings, as opposed to only 7% of individuals in this range in 2008. The decrease in young adults and children with disabilities in institutional settings suggests that these populations are either residing in a home of their own, at home with their families, or are living in more personal, or community based, home settings.

The latest OPWDD analysis (December 2010) shows 37,000 individuals living in community residences, 88,000 individuals living in their own or family home, and

1,366 individuals residing in developmental centers. Of those in developmental centers, almost 1,000 are in specialized forensics or temporary highly structured behavioral units (with a comparable size waitlist for such settings); the remaining 366 are slated for transfer to community residences by 2014 with community placement plans under development. While five developmental centers are slated for closure, it is clear that an increased capacity to provide highly structured settings for individuals with behavioral challenges is needed. At this time, temporary opportunities are envisioned that would allow the individual to stabilize and develop the adaptive skills needed for community living. The intent is to move away from campus-based options and to transition resources to support community providers as they manage risk in community settings.

TRANSPORTATION

Transportation for people with developmental disabilities is of vital importance. Dependable transportation opens up access to services, education, employment, worship, and activities within the community. Transportation services also help people live more independently, giving them greater control over their lives; this is especially the case for those living in rural areas.

A 2005 report published by the National Council on Disabilities states that the U.S. Bureau of Transportation Statistics in 2002 found that 6 million people with disabilities face barriers to transportation that affect all aspects of their lives. A population-based survey conducted by the Harris Poll in 2000 and funded by the National Organization on Disability established that approximately 30% of people with disabilities report difficulties in finding and accessing transportation, compared to approximately 10% of the general population.

The Metropolitan Transportation Authority (MTA) works to ensure that individuals with disabilities are able to access adequate and appropriate transportation through multiple programs. Descriptions of these programs are available through large print or braille brochures and audiotape in addition to sources such as the MTA website.

Individuals with disabilities unable to access public bus or subway can obtain transportation through the MTA Access-A-Ride program. Services through this program are available for individuals 24 hours a day, 7 days a week. Fares are the same as regular fare on other public transit options. Interested individuals can access obtain an Access-A-Ride ID by calling a toll free number. Once individuals have an Access-A-Ride ID, they can schedule transportation services through the program. According to the MTA 2009 Annual Report, more than 75% of their Access-A-Ride vehicles have been equipped with GPS (Global Positioning System) units that will increase the efficiency of the Access-A-Ride program through shorter wait-times for pickups as well as a reduction in fuel consumption by reducing the difficulty of finding certain destinations.

The New Freedom (NF) and Job Access and Reverse Commute (JARC) programs are funded through the Federal Transit Administration (FTA), and contained in the current federal transportation legislation, titled the Safe, Accountable, Flexible, and Efficient Transportation Equity Act: A Legacy for Users (SAFETEA-LU). They are intended to fund innovative and flexible programs and projects which

identify and address transportation needs and enhance job access of individuals with limited incomes and persons with disabilities.

Each state receives funds to cover areas with populations over 200,000 (large urbanized areas – 60% of funding), areas with populations between 50,000 and 199,000 (small urbanized areas – 20% of funding) and areas with populations under 50,000 (20% of funding). New York has six areas which receive funds from the New Freedom Grant program: Albany, Buffalo, New York City, Poughkeepsie-Newburgh, Rochester, and Syracuse.

United We Ride is an initiative sponsored by the U.S. Department of Transportation, with its partners at the Departments of Health and Human Services, Labor, and Education, for the purpose of improving the coordination and delivery of transportation services and helping transportation providers pool resources and consolidate services. In 2005, New York developed a United We Ride Action Plan. The plan emphasizes collaboration between state and federal agencies, exploration of the state's transportation needs, gathering customer and agency ideas and surveying customer needs, obtaining funding to advance mobility initiatives, and using advanced technology to support people with disabilities.

The New York State Education Department provides financial aid to schools for the transportation of students with disabilities based upon each student's Individualized Education Plan (IEP). Aid is generally provided for the transportation of students within 50 miles of their home, but aid for transportation outside of this radius may be approved on an individual basis.

The extent of unmet need, or the extent to which needed assistance is unavailable or insufficient, remains an important issue in public policy and financing of transportation support and services. Coordinated and seamless-to-the-public systems of specialized transportation with Mobility Management Centers (central information points), funding to maintain existing transportation services and maximize existing funds, and shortages of projected funding for all specialized transportation in New York are among the needs and concerns. Additionally, cross-agency coordination needs to be emphasized in order to reduce service duplication, increase service efficiency, and maximize access to services for individuals with developmental disabilities in need of transportation.

CHILD CARE

Finding appropriate and inclusive child care for children with disabilities can be a challenge for many parents in New York State. The National Early Childhood Technical Assistance Center suggests that research demonstrates that children with disabilities and their peers without disabilities benefit most from programs that are inclusive and encourage interaction between children of differing backgrounds.

In 2003, the NYS DDPC sent out a survey to agencies and individuals with expertise in the area of inclusion. Responses were used to determine the top barriers to integration/inclusion in child care settings, and the barriers identified then remain top concerns in 2010. The barriers identified through the survey were class size, staff knowledge, resources/accessibility, and transportation. While these barriers differ in nature, the root of most of these barriers was that there was a lack of funds and/or poor pay and benefits offered to staff. This survey also asked respondents to identify characteristics of successful programs so that these characteristics may be included in the development of both future and existing programs. The top three (3) identified characteristics were guardian involvement, strong inclusive missions, and teacher experience/skill.

New York State provides many supports to help families provide care for children with and without disabilities. The New York State Office of Temporary and Disability Assistance (OTDA) promotes child care subsidies to help make appropriate childcare more affordable for working families. Eligibility for these annually adjusted subsidies is based on family size and household income with local social service districts allowed to serve families with lower incomes before serving those with higher incomes where there are insufficient funds to serve all eligible families. According to the OTDA website, in addition to income eligibility, New York City, Nassau, Schenectady, Albany, Rensselaer, Oneida and Monroe County, have special funding projects, which allow these districts to provide child care subsidies to working families with incomes up to 275% of the state income standard.

The 2003 survey conducted by DDPC identified barriers and positive characteristics, but it also asked respondents to identify new strategies to increase inclusion in childcare settings. According to survey data, the most common response was that organizations should provide, or support, ongoing staff education and training. Many of these settings are likely aware of the desire for this type of training

and may have policies in place, but due to fiscal and staff issues they may lack the capacity to fully implement such trainings/educational opportunities for staff.

With the help of DDPC funding, New Alternatives for Children (NAC) implemented the “Family Forum” program and provided: a) training for foster and adoptive families in topics relevant to parenting children with developmental disabilities, b) training for agency staff working with foster and adoptive families who are parenting children with developmental disabilities, c) established parent support groups, and d) provided information and referral to community resources. As a result of activities over a 3 year period, more than 300 families and service providers received training. More than 230 families have been directly supported by program activities, and 79+ families and service providers have been active in systems advocacy related to adoption and foster care as of October 2009.

Transportation is often viewed as a major barrier to children with disabilities participating in inclusive childcare settings. However, the issue of transportation reaches across all age groups and can present challenges for individuals with all types of disability.

INFORMAL AND FORMAL SERVICES AND SUPPORTS

New York State is home to individuals from more than 170 countries and as many languages. 37% of individuals residing in the New York City area are born outside of the United States and 30% of individuals state-wide speak a language other than English.

Considering all funds, the Office for People with Developmental Disabilities (OPWDD) saw an increase of \$236,519,000 between fiscal years 2006/2007 and 2007/2008. The New York State Division of Budget cites OPWDD spending to be \$4,270,000,000 in fiscal year 2009-2010 increasing to \$4,465,000,000 in fiscal year 2010-2011. This spending increase was covered mostly by an increase in federal funding.

OPWDD provides training and respite programs to individuals with disabilities and their families through Family Support Services (FSS). In 2010, OPWDD leveraged \$82-million dollars toward FSS initiatives which is approximately \$5-million dollars more than in 2009. Increased funding for FSS helps address increasing costs associated with running such programs/supports and will help sustain these FSS services currently available.

There is a major savings initiative in place in the 2010-2011 Executive Budget which would lead to an 18% reduction in targeted case management services through OPWDD. This reduction would be tied to Medicaid Service Coordination and would increase the workloads of existing staff while evaluating the number of consumers that require MSC assistance. These reduction measures could potentially limit the amount of time MSCs can devote to an individual and this could have a negative impact as individuals with disabilities often suggest that service coordinators are most effective when they have ample time and resources at their disposal.

Language is an important, and sometimes overlooked, component of disability policy and service. This may be especially true considering the population of New York State which boasts a magnitude of individuals and much diversity. The Council of State Governments (CSG) suggests that this type of “intangible” hurdle warrants attention. CSG cites the use of “archaic” language when referring to individuals with disabilities as a major issue and New York State has worked over the last few years to reduce the use of such language. Many agencies, including

the DDPC, adhere to Person First Language, a way of writing, and speaking, about individuals with disabilities that—quite literally—places the individual before the disability in a statement. An example of Person First Language would be that “John is a person with an intellectual disability.” Additionally, agencies such as the New York State Office of Mental Retardation and Developmental Disabilities recently updated its agency name to the Office for People with Developmental Disabilities to better reflect their support of person first language.

INTERAGENCY INITIATIVES

Meeting the needs of individuals/families with cross-system or multi-system needs

The NYS DDPC, OPWDD and their partner agencies are focusing on significant issues facing individuals with developmental disabilities and their families: coordination of services when service needs cross systems and when individuals move from one system to another. The clash of cultures between systems caring for the same individuals can impact care, waste resources, and negatively impact outcomes. Additionally, there is discussion about the complex needs of youth and families, and the fact that many youths are placed out-of-state because their cross-systems needs cannot not be met within New York State. This work is supported by information from two sources as well as comments from consumers.

- The NYS Conference of Local Mental Hygiene Directors (CLMHD) surveyed individuals in counties throughout New York State to determine better approaches to address the cross-systems needs of individuals with disabilities. Narratives collected by Mental Hygiene Directors statewide suggest that individuals requiring services from multiple systems, service providers, and individuals with co-occurring disabilities face many challenges in obtaining the services they need. According to CLMHD, six categories were identified as presenting the “most challenges to cross-system collaboration, person-centered planning and access to cross-system services.” These categories include eligibility; determining the most appropriate level of care; capacity; timely service resolution; support for innovations; and funding. These have identified the following as areas in need of attention and further development: (1) How can the DD system better support people to truly make informed choices about their supports and services; (2) How do we ensure all individuals, including those with autism spectrum disorders, the aging, people with medical frailties, children, and others, are provided fair and equitable access to person centered services? (3) How do we better facilitate access to supports and services across service systems for people with multiple disability needs?
- People First Forums held throughout the state identified the need for cross-system collaboration, an issue that was shared by individuals, families, advocates, providers, and state and local government representatives. The People First Forums reinvigorated the Inter Office Coordinating Council (IOCC), established under New York State Mental Hygiene Law and comprised of representatives of the three Department of Mental Hygiene agencies, (i.e., OMH,

OPWDD, and OASAS). The IOCC aims to improve coordination of services for people with disabilities and is addressing short- and long-term goals set forth in the People First Coordinated Care Listening Forums Report (People First Report). The IOCC member agencies have asked DOH, SED, OCFS, CQCAPD and DDPC to serve as ad hoc members to address the structural, financial and regulatory barriers that limit access to services for people with multiple disabilities and cross-system needs.

To improve the range of integrated services available to children and families, DDPC and OPWDD have worked with several child-serving agencies on the Children's Plan. This plan, under the lead of the Office of Mental Hygiene contains recommendations for promoting mental health and wellness for young children, youth, and families. The result of this venture was creation of the Commissioners' Committee on Cross Systems collaboration for Children and Youth. The committee is charged with making service delivery and customer experiences better through use of integrated, coordinated service delivery. This work is supplemented by several other interagency initiatives:

- Navigating Multiple Systems – This soon to be available training builds on the success of an OMH/OPWDD program called Navigating Two Systems for adults with dual diagnosis and is based on work by DDPC. Representatives from five agencies jointly developed a framework for training agency staff, local officials, providers, and families in the various roles assumed to provide for the needs of a child with multi-systems needs. The training provides agency information, allowing trainees to contact an agency and obtain assistance with finding services.
- Respite – OPWDD also provides a broad array of services for individuals living at home with their families. These supports include respite programs, recreation, counseling, parent/caregiver training, and more. Funding for these services, known as Family Support Services (FSS), has increased for many years, growing by more than 250%, from \$23 million in 1990 to \$82 million in 2010. Many agencies serving children include respite among their services. In many cases, when a crisis occurs there may be no respite opportunity available or readily identified to meet the child's needs. An interagency workgroup is looking at the availability of interagency respite and will recommend approaches to match supply with demand, which might include opening availability across agencies.

- **Clinical Consultation Model** – This model builds on the resources of OPWDD and OMH, to provide effective cross system services in areas where there are limited resources to address the needs of children with dual diagnoses. In this model, OMH provides access to their tele-psychiatry service for dually diagnosed children. OPWDD then provides consultation on behavior therapies/interventions to address behavioral needs. A pilot of this model is being developed in the OPWDD Broome DDSO.

To strengthen cross-systems coordination efforts on a system-wide level, the CLMHD, along with OMH, OASAS and OPWDD, have made progress in the development of an integrated approach to mental hygiene planning among counties. The IOCC Mental Hygiene Planning Committee established a goal to strengthen the service system and promote coordinated care by identifying and addressing local needs while improving services for people with developmental disabilities and people confronting addiction, gambling problems, or mental illness. This planning approach provides improvements in the quality of care to individuals and their families, and reductions in administrative burdens on state and county agencies by: (1) establishing a common approach to local services and service planning, including consistent processes, overarching themes, timetables, and connections to statewide planning and budgeting; (2) exploring opportunities for collaboration focused on cross-system issues/needs of persons with multiple disabilities while supporting each agency's mission, and; (3) easing local service planning burden on counties by creating a uniform, efficient and integrated process that reduces duplication of effort and supports a rational cross-system planning focus.

Many agencies are utilizing a blended funding approach which uses funds across systems. This provides services for individuals with dual diagnoses and allows for innovation and more person-centered services. Funds allow for increased capacity based upon individual needs. This approach also promotes cross system collaboration by blending staff as well as dollars to create new services.

Funding streams for children and youth with dual diagnoses requires a review of regulatory changes and waivers that can be used to access needed services. Regulatory change includes recognition of the changing demographics of New York State, such as the increase in Autism Spectrum Disorders, and the changing resource needs of the DD workforce. It would be optimal for individuals to move across systems (e.g., in-home providers, schools, OPWDD services, mental health services) utilizing a passport system to increase efficiency in obtaining services.

Including individuals with developmental disabilities and their family members in interagency efforts is recognized as important and occurs in activities undertaken by DDPC and OPWDD.

While the environment is fertile for greater coordination and collaboration aimed at meeting the needs of individuals needing services from more than one agency, the nuts and bolts of doing so have yet to be worked out.

QUALITY ASSURANCE

Preventing abuse and neglect is a high priority goal for OPWDD and other New York State Agencies. One program created to address abuse and neglect issues is the Creating Connections initiative which began in 2008 at the Capital District DDSO. According to the 2010-2014 OPWDD Statewide Comprehensive Plan, this initiative works in collaboration with the University at Albany School of Social Welfare to strengthen the essential relationships between individuals and the staff that supports them which should reduce abuse and neglect. This initiative led to the creation of an “Assessment Toolkit” of best-practices that has been disseminated throughout New York State.

Concomitantly, DDPC was involved in the expansion of the Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment (ESCAPE). DDPC aided in the development of an ESCAPE-DD Staff Training and Curriculum Package which is meant to inform self-advocates on issues related to abuse-prevention and their rights.

The NYS Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD) is an oversight agency that monitors programs throughout New York State. CQCAPD also provides information and trainings to ensure that individuals with disabilities have the opportunity to live their lives the way they desire. According to the Executive Summary from the 2008 CQCAPD Annual Report, CQCAPD responded to over 43,000 requests for assistance, screened or reviewed over 12,000 allegations of abuse or deaths reported by mental hygiene facilities and conducted over 1,100 program reviews and independent investigations into those allegations and deaths. The New York State Division of the Budget reports that in 2007-2008 the total State Operating Funds for CQCAPD was \$14,000,000.

The Self-Advocacy Association of New York State (SANYS) is a valued partner with DDPC. DDPC worked closely in the founding and establishment of SANYS and throughout its 25 year history. SANYS has a \$1.3M budget with funds coming from New York State, membership fees, conference income, some grants and a federal AmeriCorps program. It is a well-regarded leader and partner in a broad range of advocacy efforts. Until recently, it has had a solid income from other sources and has not required operational funding or technical assistance. The current fiscal climate is likely to have an impact on SANYS and it is taking steps to streamline its operation and mission.

Concomitantly, SANYS is an integral member of DDPC advocacy and coalition efforts and a well-regarded partner of other advocacy organizations/coalitions as well. DDPC seeks input of SANYS and its members on all endeavors, including DDPC member recruitment. SANYS is a guiding member of the newly established NYS Disabilities Advocacy Association and Network.

Advocacy and Leadership are frequently involved in quality assurance initiatives. In 2009, DDPC played a key role in the development of a New York State Chapter of the National Association of Direct Support Professionals (DSPANYS). To date, more than 700 direct support professionals have joined DSPANYS in hopes of further developing their professional skills and ethics. 2009 also saw the Special Education Taskforce addressing issues related to quality assurance by increasing the number of trained special education advocates through trainings and mentoring. DDPC estimates that around 200 individuals are trained on the issue of educational rights annually.

The NYS DDPC has undertaken an initiative to increase advocacy services available to citizens; this work has spanned two decades beginning in the early 1990s with establishment of several demonstrations of independent parent advocacy networks which provided the basis for a Statewide New York State Disability Advocacy Association and Network. The latter is a cross disability advocacy resource network which required a considerable investment in a variety of information gathering, consensus building, advocacy organizational support, and other activities. The goal was to create an independent, inclusive statewide disability advocacy network to promote leadership, training and standards among advocates, and establish a clearinghouse of advocacy information and resources to increase access to support, training, public policy and leadership opportunities. Ultimately, this goal has been realized as a community of practice and support with a multi-systems orientation.

During the same period, the NYS DDPC has offered Partners in Policy Making Training Programs in its original format and in modified versions. It has been modified by the New York State Department of Health to meet the needs of discrete disability constituencies but maintains essential elements. DDPC itself has trained over 1,000 individuals or family members and has made attempts to develop and maintain a graduate network. Currently, DDPC is working with Cornell University and The Advocacy Center to move this training to a blended learning format to reach more trainees and require less travel commitments of individuals and families. The grantees have developed a website to facilitate this learning for-

mat as well as a more-supportive experience for Partners graduates. Partners graduates participate in continuing education webinars (and other trainings) offered by the grantee, mentor individuals in the current Partners class and exchange ideas with other Partners graduate registered on the password-protected website.

Individuals with disabilities in the prison system can be a difficult group to provide with supports and services. Many of these individuals have undiagnosed intellectual, or developmental, disabilities and may not have the proper medical records to obtain some services. As of 2010, it was estimated that the number of individuals in the prison system is around 58,000. The New York State Department of Correctional and Community Services (DOCCS) operates three special needs units (or SNUs). The total number of SNU beds available between these three sites is approximately 166; these units help inmates with DD who may not be able to function safely in the general prison population.

The DDPC is working to improve the lives of individuals with disabilities recently released from prison, as well as those still incarcerated, by linking them with provider agencies to assist them in receiving the services and supports they need. Inmates with disabilities such as serious mental illness and/or developmental disabilities, experience a rate of recidivism near 50%. A recent OMH study showed that with comprehensive discharge planning, inmates with serious mental illness returned to prison at a lower rate (38% compared to 50%). This reduction in individuals returning to prison post-release reduces DOCCS costs and helps these individuals participate in more meaningful ways in the community with the proper services and supports in place. This is an outcome that DDPC and DOCCS are hoping to replicate for inmates with developmental disabilities.

RECREATION

With much focus given to housing, employment, and health issues, sometimes fewer resources are dedicated to issues related to recreation/leisure for individuals with disabilities. However, participation in recreation options is an important part of life. As services and supports are increasingly threatened, the need for recreation outlets and options is increasing. The New York State Inclusive Recreation Resource Center (NYSIRRC), headquartered at the State University College at Cortland, promotes the participation of individuals with disabilities in recreational activities of their choosing. NYSIRRC provides a one-day training program called Inclusion U. Upon completion of the Inclusion U training curriculum, graduates are considered “Inclusivity Assessors” and can begin assessing recreational options using the NYSIRRC Inclusivity Assessment Tool. More than 1,000 people have attended Inclusion U training and 970 people have passed the final exam to become Certified Inclusivity Assessors. Many individuals participating in the training have been students (450+) and this may serve to introduce a new generation of students/graduates to the difficulties sometimes encountered by individuals with disabilities in recreational settings. Once a recreational site is assessed, it can be added to the NYSIRRC inclusive recreation online database which currently contains more than 300 sites and has been visited 8,491 times as of September 2010. The database lists more than 150 sites in the Finger Lakes area, more than 35 sites in Central NY, more than 35 sites in the Hudson Valley area, and 30 sites in the New York City area. The large number of sites in the Finger Lakes region versus other areas of New York State can be attributed to the geographic location of this Cortland-based program.

An ADA lawsuit to obtain motorized access to the Adirondack Forest Preserve led to considerable improvement to recreation facilities in New York State North Country region. One of the provisions of the settlement, offered by the Department of Environmental Conservation (DEC), was to construct 185 accessibility projects in the Adirondacks and Catskills. Among the other major requirements under the settlement, DEC agreed to hire a full-time Access Coordinator; coordinators in each of the nine regions across the state; form an accessibility advisory committee; provide training to staff in designing accessible elements and disability awareness; provide training to licensed guides and vendors of services in the Forest Preserve; educate the public on the existence of the new opportunities; involve organizations that serve people with disabilities in unit management planning and prepare a number of unit management plans for public review.

Since that time, DEC has constructed over 200 accessible outdoor recreation sites on state lands. Many of the Adirondack sites were part of a legal settlement which was completed in 2009. The sites provide access to programs such as fishing, hunting, camping, canoeing, horseback riding, picnicking, boating, hiking and wildlife viewing. The DEC Universal Access Program has continued to provide an active and focused approach to providing access to all programs and services. Education, direct outreach and experiential programs are a priority. DDPC grants enabled the New York State Inclusive Recreation Center to provide training to DEC staff across the state to continue self-evaluation and transitions plans for all planning units.

In a similar vein, International Paper donated a 16,000-acre conservation to New York State for the development of the International Paper John Dillon Park as the first Adirondack park designed specifically to be accessible for individuals with disabilities. John Dillon Park provides a range of sleeping environments and trails that were designed with accessibility in mind. Overnight stays in John Dillon park are provided at no cost to patrons and an endowment fund is being set up to ensure that individuals can continue to use the park free-of-charge in coming years.

UNSERVED AND UNDERSERVED GROUPS

Under the Developmental Disabilities Assistance and Bill of Rights Act, the DDPC is required to identify and assist un-served and under-served populations as a means of improving the services and supports available to them. Thus, the following groups and barriers receive special attention in ongoing efforts.

General Racial / Ethnic Barriers

Individuals that identify themselves as “Multi-Cultural,” or of more than one racial group. New York State is home to individuals from 178 different countries and 170+ languages are spoken with 30% of the population speaking languages other than English; 1/3 of the population is from minority groups with an increasing Hispanic presence and 37% of individuals residing in NYC alone are foreign born. There has been a long-standing recognition that individuals with developmental disabilities and their families from ethnic or racial minority groups are not well served by the service delivery system. The extreme density and diversity of the population has compounded the difficulties. While there have been extensive efforts to rectify this situation, there is still a considerable amount of work to be done to improve the cultural sensitivity and responsiveness of the service system for these groups.

General Barriers

DDPC analysis shows that individuals from the following groups are likely to be underserved. Perceived barriers to needed services and supports include: workforce quantity, quality, turnover and skills, including skill development for facilitating self-determination; service system capacity to deal with multiple, severe, concurrent, and unusual disabilities; and no mechanisms to facilitate coordination across service systems.

- **Group:**

Children and adults with developmental disabilities requiring services from multiple service systems. This group includes individuals with any kind of dual diagnosis and/or multi-system need(s).

- **Barrier:**

These consumers and their families report difficulty in obtaining adequate and appropriate services to meet their needs and desired ease of access, cross systems continuity and coordination.

UNSERVED AND UNDERSERVED GROUPS

General Barriers

(Continued...)

- **Group:**

Children and adults with developmental disabilities and challenging behaviors.

- **Barrier:**

Families of these individuals report that these behaviors significantly deter accessing needed services and are often cause for service suspension, disruption and/or delay.

- **Group:**

Individuals with functional disabilities who may not be eligible for New York State DD services but may benefit from supports.

- **Barrier:**

This group includes individuals who fit the federal definition of developmental disabilities but not NYS OPWDD eligibility criteria. These individuals note that their disability significantly restricts their functional capacity and ways of accessing natural and generic community supports would assist them in their activities of daily living.

- **Group:**

Individuals with developmental disabilities who are otherwise eligible but are not receiving services because of geographic barriers.

- **Barrier:**

These individuals report transportation and distance as significant barriers to receipt of services and they have difficulty finding workers willing to travel to their homes.

**New York State
Developmental Disabilities
Planning Council**

***Goals
and
Objectives
by
Portfolio***

**State Plan
2012-2016**

RATIONALE FOR GOAL SELECTION

The DDPC has chosen to work strategically under an investment portfolio approach in our work. We have chosen to work under 5 portfolios with 6 goal statements developed for one of two reasons: 1) the DDPC has a long-term commitment in that area; or 2) public input identified it as an area of concern. Of the chosen 5 portfolios and 6 goals, DDPC has had long term agendas in the areas of systems transformation, transitions, community inclusion, healthy living and advocacy and leadership (including self-advocacy). While not new to the DDPC, work under each goal has been expanded or moved in different directions based on public input.

DDPC initiated the state plan development process looking carefully at its current and past work to identify efforts needed to get to the desired point in each area of concern. Members and staff sought input from our state's consumers, families, organizations and collaborators on pressing priorities and received a wealth of information; additionally, an extensive amount of literature was reviewed. This massive body of information was cataloged and sorted extensively until the ultimate five portfolios and six goal statements with concomitant objectives and implementation activities were devised and fully developed.

In the course of its deliberations, the DDPC identified a few critical factors in refining its proposed work under each goal statement:

- a specific and defined role for DDPC
- likelihood of goal achievement within expected resources
- economic realities and likelihood of sustainability
- a unique contribution to a larger solution or benefit in pooled resources

In moving from the review of current and past work to its expansion and movement into new directions, extensive outreach and information gathering activities were undertaken.

Review of human services state plans, focus groups with collaborators, and information solicited from statewide organizations identified a wide range of issues and concerns but highlighted need for effort in a few notable areas:

- Skill building and laying the groundwork for employment and post-secondary opportunities;
- Addressing the issues faced in obtaining/securing safe, accessible, and affordable housing in an era of fiscal uncertainty;

- Investigating eligibility concerns and assisting individuals and families to access needed services and supports provided in inclusive environments;
- Concerns related to independence including flexible and individualized supports in less restrictive settings
- Lack of awareness of services and supports available to individuals and families.
- Need to strengthen cross-systems approaches and cross-disability service delivery, including dual diagnoses and transitions.

The latter was found to be pervasive across all stakeholder groups. Individuals with needs that span more than one service delivery system has been an identified un-/under-served population in the last three NYS DDPC planning cycles and joint county level mental hygiene planning (DD, mental health, substance abuse) identified cross systems coordination as the highest priority activity surpassing even access to services. The sophistication of the New York State service delivery environment with the current economic climate is exacerbating an already troublesome situation.

As always, self-advocates were anxious to share their experiences and concerns with us – at existing venues and special solicitations.

- When surveyed on needed self-advocacy skills, tools, resources or supports, they requested assistance with:
 - gaining access to elected officials and policymakers,
 - peer-mentoring and more opportunities to get information and training,
 - better understanding of Medicaid, Medicare, and Social Security,
 - an on-line community to increase communication between caregivers, agencies, and self-advocates, and
 - increased involvement with peers without disabilities from a young age.
- Focus group discussions yielded additional needs and concerns related to need for:
 - more seminars/meetings/guides on available services;
 - training on speaking constructively;
 - assistance in navigating the system;
 - supports to individuals who are balancing choice and responsibilities – particularly when families, siblings, and providers would prefer not to change services and the individual would;
 - better explanation of health conditions and options;
 - more opportunities for choice; and
 - clarification of the staff role as facilitator rather than decision maker;

- community attitudes.
- In addition, this well-established statewide self-advocacy organization has asked for continued assistance in support of agendas on:
 - increasing community participation and natural supports,
 - individualized supports,
 - youth advocacy development,
 - shared living, and
 - employment.

Thus, the work under the advocacy and leadership development goal and self-advocacy and leadership development goal was combined under a single portfolio with compatible objectives and activities. And support for key self-advocacy agendas is infused throughout the entire 2011-2016 DDPC State Plan.

When asked to assist in priority setting, the New York State developmental disabilities community validated our intent to work in five areas and identified the highest priority areas for that work as:

1. Goal – Systems Transformation with Sustainable Supports
 - Self-determination/self-direction with flexible supports
 - Residential options
 - Lifelong learning and post-secondary opportunities
 - Workforce development
2. Goal – Life Transitions and Cross Systems Coordination
 - Transitions across the lifespan
 - Multi-system needs of individuals -access/ease/coordination/improved services and supports
 - Multi-systems approaches to service delivery (focusing on the organization and systems levels)
 - Educational services and supports
3. Goal – Community Inclusion and Participation
 - Employment
 - Community development and training (natural supports/sensitivity/awareness/ inclusion)
 - Natural and community supports
 - Inclusive opportunities (recreation, congregations, first responders, volunteerism, etc.)
 - Transportation
4. Goal – Healthy Living
 - Health and Wellness (nutrition, fitness, self-management, chronic disease management, etc.)

- Behavioral health and crisis intervention
 - Training for health care workers
 - Oral/dental health
 - Emerging approaches to health care (including electronic options)
5. Goal - Leadership, Advocacy, and Informed Decision Making
- Coalition building and network development (cross-disability, family, siblings, fathers, etc.)
 - Training and Leadership Development (including individual/family-professional partnerships)
 - Informed decisions and access to information

Thus, objectives and implementation activities were developed in each of the areas identified under the priority setting survey.

A comprehensive background paper has been developed for each of the 5 portfolios that includes a review of the literature and existing survey findings, the state situation, review of relevant state and provider agency plans, past DDPC efforts and lessons learned, and implied directions.

Notably, as this planning document was developed, the service delivery environment in New York State has been in a great deal of upheaval that is explained largely in terms of the state budget deficit. The most immediate action is an across the board reduction in services and workers with an impact yet to be determined. In addition, two major structural efforts have been undertaken:

- a massive Medicaid Redesign effort which was initiated in the first few days of 2011 under newly elected Governor Andrew Cuomo’s administration; and
- the potential for consolidation of several state agencies, including the state DD agency.

While this plan was considered “doable with a BIG stretch” while being developed, the above noted factors, when they become reality, may have a significant impact on the work that we can do; thus, annual reassessment will be essential.

Portfolio:
***SYSTEMS TRANSFORMATION WITH
SUSTAINABLE SUPPORTS***

Goal and Objective Statements

- **Goal 1:** Demonstrate strategies and approaches that empower and increase the ability of individuals with developmental disabilities and their families to establish, lead, and sustain self-directed and meaningful lives.

Specific Objectives:

- **1.1** - Self-direction and individualized supports—Individuals who have a self-directed life will increase by 200%
- **1.2** - Residential options—Increase the number of adults with developmental disabilities in non-certified community-based individualized housing and support options by 5-10%.
- **1.3** - Lifelong learning and post-secondary opportunities—Identify and address four (4) policy, practice or funding barriers inhibiting successful participation of individuals with DD in lifelong learning opportunities and post-secondary educational experiences.
- **1.4** - Workforce development—Improve the quantity, quality, and stability of the DD workforce by addressing four (4) persistent workforce concerns.

Portfolio:
***LIFE TRANSITIONS AND CROSS
SYSTEMS COORDINATION***

Goal and Objective Statements

- **Goal 2:** Improve the availability, ease, coordination, and effectiveness of life transitions and supports across all service delivery systems and all stages of life.

Specific Objectives:

- **2.1** - Transitions—Increase the resources and assistance available to individuals with DD making transitions in at least eight (8) life transition areas.
- **2.2** - Multi-systems needs of individuals—Resolve at least three (3) policy, practice or funding barriers that improve availability, ease, coordination, and/or effectiveness of services for individuals with multi-system needs.
- **2.3** - Multi-systems approaches to service delivery (organization and systems levels)—Address at least four (4) program, funding or policy barriers which affect individuals with complex behavioral and medical needs to transition into adult services using a multi-stage process (potentially replicable for other populations).
- **2.4** - Educational services and supports—Address at least four (4) policy, practice, or funding barriers to assure more individualized educational opportunities for children with DD.

Portfolio:
***COMMUNITY INCLUSION
AND PARTICIPATION***

Goal and Objective Statements

- **Goal 3:** Increase full inclusion of individuals with DD in community life.

Specific Objectives:

- **3.1** - Employment—Reduce by 5% the gap in employment rate for people with developmental disabilities in relation to employment levels within the general population.
- **3.2** - Community development/training—Engage in at least four (4) community development activities intended to increase full inclusion of individuals with DD in community activities.
- **3.3** - Natural and community supports—Identify and promote at least three (3) effective practices for increasing the natural and community supports available to children and adults with DD wishing to participate in community activities.
- **3.4** - Inclusive opportunities—Improve opportunities for person-centered and meaningful community participation and engagement for individuals with developmental disabilities in at least five (5) areas of community life.
- **3.5** - Transportation—Address at least four (4) transportation-related policy, practice, or funding barriers to employment or community participation for people with developmental disabilities.

Portfolio:
HEALTHY LIVING

Goal and Objective Statements

- **Goal 4:** Increase and improve access to and availability of appropriate and quality health promotion and health care for individuals with developmental disabilities.

Specific Objectives:

- **4.1** - Health and wellness—Identify and demonstrate or promote replication of at least six (6) innovative or promising practices that improve access to and availability of appropriate and quality health care and wellness for people with DD and their families.
- **4.2** - Behavioral health and crisis intervention—Address four (4) policy, practice or funding systems barriers to improve outcomes for children and/or adults with behavior challenges.
- **4.3** - Training for health care workers—Training for at least 500 health-related personnel will include disability content and direct experiences with children and adults with developmental disabilities and their families/caregivers.
- **4.4** - Oral/dental health—Training for at least 350 oral health-related personnel which improves access to and availability of appropriate and quality oral health care for people with developmental disabilities.
- **4.5** - Emerging approaches to health care—Identify and encourage use of five (5) emerging approaches to health care that increase access to appropriate health care and health promotion activities for individuals with developmental disabilities.

Portfolio:
***LEADERSHIP, ADVOCACY, AND
INFORMED DECISION MAKING***

Goal and Objective Statements

- **Goal 5:** Increase and strengthen disability advocacy network and leadership development and informed decision making.

Specific Objectives:

- **5.1** - Coalition building and network development—Encourage development and strengthening of at least six (6) developmental disabilities advocacy network organizations/entities and assure linkages to cross disability efforts.
- **5.2** - Training and leadership development—Develop and present needed leadership and advocacy training and skill building opportunities for at least 5000 individuals with developmental disabilities and family members annually.
- **5.3** - Informed decisions and access to information—Promote informed decisions and improve access to needed information for individuals with developmental disabilities, families and interested others utilizing at least five (5) strategies.

Portfolio:
***LEADERSHIP, ADVOCACY, AND
INFORMED DECISION MAKING***

Goal and Objective Statements

- **Goal 6:** Increase and strengthen self-advocacy networks, leadership development and informed decision making.

Specific Objectives:

- **6.1** - Support of self-advocacy—Work to strengthen the capacity of self-advocacy organizations led by and for individuals with developmental disabilities in at least five (5) areas identified by self-advocates.
- **6.2** - Leadership development—Using at least four (4) strategies identified by self-advocates, provide opportunities for individuals with developmental disabilities who are considered leaders to guide, mentor or train individuals with developmental disabilities who potentially may become leaders.
- **6.3** - Cross-disability coalitions—Expand participation of individuals with developmental disabilities in at least five (5) cross-disability and/or culturally diverse leadership or disability advocacy coalitions.



**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. 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, 2012-2016, 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)

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 links.
- Letters of intent are typically requested from agencies that are interesting 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

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

...Continued..

Request for Proposal (RFP) Process...continued

- **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.**



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 34 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. 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 DDPC 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'RE 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: _____

**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 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

Comments Section

NYS Developmental Disabilities Planning Council State Plan 2012-2016

- *What do you think of our plan...*

- *Suggestions to assist in achieving the goals and objectives in our plan...*

Please copy or remove completed section and Mail, Email or Fax to:

**Anna Lobosco
NYS DDPC
99 Washington Avenue - 12th Floor - Suite 1230
Albany, NY 12210**

**Email: ddpc@ddpc.ny.gov
Fax: (518) 402-3505**

NYS DDPC 2012-2016 State Plan Acronym Listing

AAA – Area Agencies on Aging

ACCES-VR – Adult Career and Continuing Education Services – Vocational Rehabilitation

ACOG – American Conference of Obstetricians and Gynecologists

ACS – American Community Survey

ADD – Administration on Developmental Disabilities

ADL – Activities of Daily Living

AHRC – Association for the Help of Retarded Children

APSE – Association for Persons in Supported Employment

ASD – Autism Spectrum Disorders

AT – Assistive Technology

CAH – Care at Home

CBVH – Commission for the Blind and Visually Handicapped

CHP – Child Health Plus

CLMHD – Conference of Local Mental Hygiene Directors

CMS – Centers for Medicare and Medicaid Services

COGME – Council on Graduate Medical Education (in the Department of Health)

CQCAPD – Commission on Quality of Care and Advocacy for Persons with Disabilities

CRA – Comprehensive Review and Analysis

CSG – Council of State Governments

CSS – Consolidated Supports and Services

DC – Developmental Center

DD – Developmental Disability/Developmental Disabilities

DDPC – Developmental Disabilities Planning Council

DEC – Department of Environmental Conservation

DEP – Disability Employment Program (at Department of Labor)

DHCR – Division of Housing and Community Renewal

DME – Durable Medical Equipment

DOCCS – Department of Corrections and Community Supervision
DOH – Department of Health
DOL – Department of Labor
DSP – Direct Service Provider
DSPANYS – Direct Support Professional Alliance of New York State
EDI – Employment and Disability Institute
EI – Early Intervention
ESCAPE – Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment
ESEP – Enhanced Supported Employment Program
ETP – Employment Training Internship Program
FASD – Fetal Alcohol Spectrum Disorders
FFY – Federal Fiscal Year
FSS – Family Support Services
FTA – Federal Transit Administration
GED – General Education Development tests
GPS – Global Positioning System
HCBS – Home and Community Based Services
HOYO – Home of Your Own
HSRI – Human Services Research Institute
HUD – Department of Housing and Urban Development
IADL – Instrumental Activities of Daily Living
ID – Intellectual Disabilities
IDEA – Individuals with Disabilities Education Act
ILC – Independent Living Center
IRWE – Impairment Related Work Expense
JARC – Job Access and Reverse Commute
LDA NYS – Learning Disabilities Association of New York State
LTC – Long Term Care
MH – Mental Health / Mental Hygiene
MISCC – Most Integrated Setting Coordinating Council
MSC – Medicaid Service Coordinator
MTA – Metropolitan Transportation Authority
NAC – New Alternatives for Children

NCI – National Core Indicators
NF – New Freedom
NYC – New York City
NYMWP – New York Makes Work Pay
NYS – New York State
NYS CARES – NYS Creating Alternatives in Residential Environment and Services
NYS IRRC – NYS Inclusive Recreation Resource Center
NYSACRA – New York State Association of Community and Residential Agencies
NYSDAAN – New York State Disabilities Advocacy Association and Network
NYSED – New York State Education Department
NYSSB – New York State School for the Blind
NYSSD – New York State School for the Deaf
NYSTRA – New York State Therapeutic Recreation Association
OASAS – Office of Alcohol and Substance Abuse Services
OCFS – Office of Children and Family Services
OMH – Office of Mental Health
OPWDD – Office for People with Developmental Disabilities
OTDA – Office of Temporary and Disability Assistance
P & A – Protection and Advocacy
PAP – Papanicolaou test
PDA – Personal Digital Assistant
PHE – Partners in Health Education
PPR – Program Performance Report
PSA – Public Service Announcement
PSA Test – Prostate-Specific Antigen
PTIC – Parent Training and Information Centers
RFK UCEDD – Rose F. Kennedy University Center for Excellence in Developmental Disabilities (at Albert Einstein College of Medicine)
RRTI – Rehabilitation and Research Training Group
SAFETEA-LU – Safe, Accountable, Flexible, and Efficient Transportation Equity Act: A Legacy for Users
SANYS – Self Advocacy Association of New York State
SCDD – Strong Center for Developmental Disabilities (at the University of Rochester)
SED – State Education Department

SEPTA – Special Education Parent Teacher Association
SFY – State Fiscal Year
SIPP – Survey of Income and Program Participation
SNU – Special Needs Unit
SSA – Social Security Administration
SSDI – Social Security Disability Insurance
SSI – Supplemental Security Income
SUNY – State University of New York
TBI – Traumatic Brain Injury
TRAID – Technology Related Assistance for Individuals with Disabilities
UCEDD – University Centers for Excellence in Developmental Disabilities
USDA – United States Department of Agriculture
VESID – Vocational and Educational Services for Individuals with Disabilities
VR – Vocational Rehabilitation
WIA – Workforce Investment Act
WIHD – Westchester Institute for Human Development (with New York Medical College)



Great Seal of the State of New York

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**1-800-395-DDPC (3372)
Toll Free Voice and TDD/TTY
(518) 486-7505 (VOICE)
(518) 402-3505 (FAX)**

Website: www.ddpc.ny.gov