



State Plan

2007-2011

of the

New York State Developmental Disabilities Planning Council

Governor David A. Paterson

Sheila M. Carey
Executive Director

George E. Fertal, Sr.
Chairperson

Rose Marie Toscano
Vice-Chairperson

A message from the...

Chairperson & 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) 2007-2011, a plan that will bring us to the Council's 40th anniversary in 2011.

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 be, to advise governors and State agencies on the use of available and potential resources to meet the needs of individuals with developmental disabilities.

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 demonstration of new approaches to enhance their 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 2007-2011 State Plan to fruition by partnering with the DDPC. We also look forward to receiving concepts that you may have that will help in achieving the goals, objectives, and concepts that may go beyond the stated goals and objectives. Certainly, our mandate is to fulfill the stated goals and objectives but we are always interested in new concepts.

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,



George E. Fertal, Sr.
DDPC Chairperson



Sheila M. Carey
DDPC Executive Director

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**New York State
Developmental Disabilities
Planning Council**

David A. Paterson, Governor

George E. Fertal, Sr., Chairperson

Sheila M. Carey, Executive Director

Submitted to:

Administration on Developmental Disabilities

July 21, 2006

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PERSKE: PENCIL PORTRAITS 1971-1990

(Nashville: Abingdon Press, 1998)

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, 2006 to September 30th, 2011 and covers federal fiscal years 2007, 2008, 2009, 2010 and 2011.

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 2007-2011 New York State Developmental Disabilities Planning Council's State Plan is to:

- meet the requirements set down by Congress that States wishing to participate in Part B of the Developmental Disabilities Assistance and Bill of Rights Act must comply with the provisions of this law;
- 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 policies while 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 the 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 the previous decade;
- 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 agencies, 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 2007-2011 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 added by 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 34 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 principle state agencies, University Centers for Excellence, the Protection and Advocacy Agency (P&A), higher education training facilities, 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. This document contains: both a listing of the members of the DDPC and a listing of DDPC staff.

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 NYS Office of Mental Retardation and Developmental Disabilities (OMRDD), and other relevant state agencies to ensure interagency coordination of activities and to promote systemic change.

The current DDPC Chairperson and Executive Director are:

George E. Fertal, Sr., Chairperson

NYS Developmental Disabilities Planning Council
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~ Consumer Members ~

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Patricia Edelstein
Virginia M. Ellis
George E. Fertal, Sr., *DDPC Chairperson*
Tamelia Laquana Fritz
Shirley Goddard
Angela F. Harmer
Victoria M. Hiffa
Dr. Diane Iwaniec
Kevin Kennedy
Aldea LaParr, *DDPC Consumer Caucus Chairperson*
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~ Non-Governmental Agency Member ~

Pamela B. Conford, M.S., C.S.W.

~ University Centers for Excellence Members ~

Ansley Bacon, Ph.D.
Philip W. Davidson, Ph.D.
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~ **State Agency Members** ~

Honorable Deborah VanAmerongen
Acting Commissioner
NYS Division of Housing & Community Renewal

Honorable David A. Hansell
Acting Commissioner
NYS Office of Temporary and Disabilities Assistance

Honorable Brian S. Fisher
Acting Commissioner
NYS Department of Correctional Services

Honorable Michael J. Burgess
Director
NYS Office for the Aging

Honorable Astrid C. Glynn
Acting Commissioner
NYS Department of Transportation

Honorable Diana Jones Ritter
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NYS Office of Mental Retardation and Developmental Disabilities

Honorable Richard P. Mills
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Honorable Dr. Richard F. Daines, M.D.
Acting Commissioner
NYS Department of Health

Honorable Gary O'Brien
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NYS Commission on Quality of Care and Advocacy
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Sharon Winchester, Research Assistant

Kerry Wiley, M.S.W., Research Assistant

Jane Muthumbi, Ph.D., Project Assistant

Mary Sampson, Agency Program Aide

Nathaniel Douglas, Keyboard Specialist

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.

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** (Areas of Emphasis - All)
- **Review Prior Work of the DDPC Standing Committees & Workgroups for Relevant Findings** (Areas of Emphasis - All)
- **Obtain & Review Public Forum Summaries** (Areas of Emphasis - All)
 - ◆ NYS Office of Mental Retardation and Developmental Disabilities (OMRDD) Constituent Forums
 - ◆ Most Integrated Setting Coordination Council Forums
 - ◆ OMRDD 5 Year Plan Hearings
 - ◆ Transportation
 - ◆ Fetal Alcohol Spectrum Disorder (FASD)
 - ◆ OMRDD Housing Regional Forums
 - ◆ Vocational and Educational Services for Individuals with Disabilities (VESID) Town Hall Meetings
 - ◆ IDEA Public Meetings
 - ◆ Maternal Child Health Assessment
 - ◆ Self-Advocacy (SANYS) Statewide Conference
- **Review Existing Survey Results**
 - ◆ DDPC Consumer Satisfaction
 - ◆ National Council on Disability
 - ◆ NYS Association of Community & Residential Agencies
- **Individual & Family Survey** (Areas of Emphasis - All)
 - ◆ Paper and web-based option

- **Provider Survey (Areas of Emphasis - All)**

- ◆ Web-Based with Paper Option

Priority Setting

- **External Focus Groups**

- ◆ 6 Regional Self-Advocacy Association of New York State (SANYS) Conferences
- ◆ Parent-to-Parent, Family Support Services (FSS) Regional Conferences
- ◆ Statewide Organization Conferences

- **Internal Focus Groups**

- ◆ June 2005 and 2006 DDPC Work Sessions

Collaborations

- New York State Planning Effort for the Alliance for Full Participation (AFP) Summit (Areas of Emphasis - All)
- Developmental Disabilities Network & Other State Agency “Plans” (Areas of Emphasis - All)
- Input From Developmental Disabilities Network Partners (i.e. Protection & Advocacy Board, University Centers for Excellence Consumer Panels)
- Other - as necessary and available

Public Comment

- **Public Comment Period**

- ◆ Mail & Web-based Options

New York State Service System for People with Developmental Disabilities



NEW YORK STATE SERVICE SYSTEM

ECONOMIC FACTORS

Overnight, the New York State economy went from a period of unsustainable economic growth into a long slow recovery from the September 11, 2001 collapse of the World Trade Center. This has had a significant and pervasive impact on the New York State policy and fiscal environment. A policy of fiscal discipline has been in force that includes restrained spending, debt reform, and a smaller state workforce. While the New York State “rainy day” fund has been restored to the pre-9/11 level, tax receipts are slightly higher than anticipated, and the state credit rating is at its highest in 30 years; state spending, job and personal income growth are all less than the national average. The New York State economy is gaining jobs in the securities, technology and bio-technology fields, but rapidly losing manufacturing jobs resulting in fairly flat economic growth – a trend across the Northeast.

New York State has the 11th largest economy in the world. A recent survey of employers, however, found them not optimistic about economic growth. Major concerns were labor and energy costs, tax and regulatory burden, and availability of skilled labor. New York State is using tax reductions, targeted investments and incentives, greater emphasis on electronic access to government and a concerted effort to reduce reliance on petroleum to ensure that New York State remains an economic power able to compete on national and global scales for business investments and jobs.

Of key concern to the developmental disabilities field are proposed state and federal Medicaid changes. New York State is gradually assuming the local share of Medicaid to provide budgetary relief to localities. Initiatives to contain escalating Medicaid costs are being implemented and an Office of Medicaid Inspector General was established to strengthen State Medicaid program integrity. Despite economic variability and threatened Medicaid cuts, the New York State developmental disabilities service system has been maintained and seen some growth through use of both state and federal sources of support.

SOCIAL FACTORS

New York State is a diverse and complex state of about 18 million residents. Half live in the New York City metropolitan area while the remainder populates more rural and suburban upstate counties. Major ethnic groups are represented—about 52% white (though non-Hispanic whites are not in the majority overall); Blacks 29%; Asians 7%; Hispanic people of all races make up 24%; a million people belong to other racial groups; and 28% are foreign immigrants. The resultant multi-lingual society presents significant challenges.

The makeup of New Yorkers with developmental disabilities reflects the larger population. This diversity challenges efforts to meet service needs and develop and maintain a culturally sensitive and responsive system. These individuals are also affected by the concepts of community inclusion, self-advocacy, self-determination and the changing structure of the family.

New York State has a strong self-advocacy association that is accepted as a partner at the policy level with potential for an even stronger role. Self-determination initiatives are ongoing with policy, regulations and funding slowly moving in the direction of greater flexibility and self-direction. These efforts increase consumer and family involvement in decision making. Organizational and workforce skill in facilitating self-determination is not yet strong enough to sustain this model.

Inclusion of people with developmental disabilities in community activities is accepted at the policy level. However, community attitudes and the ability of the community and community agencies to facilitate inclusion need to be bolstered for real physical and programmatic inclusion to occur.

The changing structure of the family has seen more single parent and grandparent-headed households and two income families. This has changed the types, duration, and intensity of services required. Also, families of young children have an expectation that inclusive community and residential services will be available for their children when they reach adulthood.

POLITICAL FACTORS

In recent years, the service system for New Yorkers with developmental disabilities and their families has been enhanced by policies, budgets and programs that have addressed the growing waiting list for residential services; infused person centered planning approaches to assure development of smaller, individualized service environments; provided additional day services, service coordination, and family supports; and included monetary and programmatic incentives for workforce stability and improvement. However, there is still significant need.

While the closing of developmental centers has slowed, remaining residents tend to have multiple and severe disabilities with significant medical/behavioral involvement that requires more intensive, specialized services that are harder to develop. The need for special units for individuals with significant behaviors, involvement with the criminal justice system, and greater cross-systems collaboration in serving individuals needing services from more than one service system are evident.

Current threats to Medicaid have increased the concern of the consumer, provider and policy communities. Thus, advocacy efforts are on the rise. Training programs, such as Partners in Policymaking, have served to increase consumer involvement in federal, state and local policy making. In addition, a new advocacy resource network is being established to provide technical assistance and information to regional advocacy programs/networks to better meet the needs of consumers and family members.



LITIGATIVE FACTORS

Several New York State court decisions have served to foster the tenets of the Americans with Disabilities Act (ADA), Olmstead Supreme Court Decision, Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973. The New York State Protection and Advocacy network has played a critical role in pursuing litigation to established key precedents on a variety of disability issues. For example:

- The Federal Court of Appeals for the Second Circuit ruled that under Olmstead, a residential facility should be found closer to the family home. In the interim, parents should receive funds to cover expenses incurred while visiting their child at an out of state facility.
- New York State Education Department Office of Vocational and Educational Services for Individuals with Disabilities (VESID) agreed to revise its due process notices to indicate that there is a ninety day deadline in which to file an appeal.
- In *E.W. v. Staten Island University Hospital*, full accessibility to hospital services has been assured for individuals with developmental disabilities. The final settlement has been placed in a Trust for all named plaintiffs.
- The Fourth Department re-defined the standard for Durable Medical Equipment (DME) as restoration to normal function (increase ability to lead a normal life) and that restoration is a medical benefit.



EDUCATION & CHILD DEVELOPMENT

The scope of educational services in New York State is primarily the responsibility of the State Education Department (SED). Collaborative efforts with the Office of Mental Retardation and Developmental Disabilities (OMRDD), the Office of Mental Health (OMH), the DDPC, the Office of Children and Family Services (OCFS), and the Department of Health (DOH) have strengthened the array of services for children with developmental disabilities and their families. These initiatives include:

- early intervention (DOH),
- services for pre-school through college and adult education (SED),
- childcare, foster care and adoption services (OCFS),
- family supports (OMRDD & OMH), and
- public education and consumer training (DDPC).

New York State provides a spectrum of special education and related services to children 0 to age 2 through the Department of Health and for students from 3 to 21 years of age under the purview of the State Education Department Office of Vocational and Educational Services for Individuals with Disabilities (VESID). The proposed 2006-2007 New York State Budget includes efforts to improve access to less restrictive environments, improve early intervention, reduce out-of-state placement of children, expand family support and respite services. Inter-agency efforts to coordinate services to children across multiple service systems is the purview of the Coordinated Children's Services Initiative (CCSI) which functions at the local, regional and state policy levels.



HEALTHCARE

The State health system goal is to ensure availability of high quality and appropriate health services at reasonable cost to all New York State residents. The Department of Health (DOH) is charged with promoting and supervising public health activities, ensuring high quality medical care in a sound and cost effective manner, reducing incidence and negative outcomes of infectious disease, and directing a variety of homeland security measures to assure readiness for response to potential public health threats.

DOH administers the State Medicaid Program and the Maternal and Child Health Block Grant. It also administers health and wellness; managed care; traumatic brain injury; pharmaceutical and health care worker certification, education and training; medical home; health facility, hospital, and nursing home oversight; managed care; and long term care programs. Current priorities are preparing for health emergencies, long term care reform stabilization, expanding managed care, and comprehensive Medicaid integrity planning including cost controls, increased in-home services, and pharmaceutical savings.

Greater efforts are being placed on improving health and wellness, preventing secondary disabilities, and dealing with the effects of aging, including need for end-of-life care and hospice services.



EMPLOYMENT

The Department of Labor (DOL) helps prepare people for jobs of today and tomorrow. It delivers many services that help people to find jobs and employers to find workers, including welfare employment services programs. Collaboration among a variety of agencies supports the State goal of meaningful and gainful employment for all citizens.

The lead state agencies for vocational and employment training at the secondary and post-secondary levels are the State Education Department Office of Vocational and Educational Services for Individuals with Disabilities and the Commission for the Blind and Visually Handicapped. These agencies provide vocational rehabilitation services tailored to the individual goals, capabilities, and needs of people with disabilities. The Office of Mental Retardation and Developmental Disabilities (OMRDD) maintains responsibility for adults with developmental disabilities employed in integrated, supported and sheltered work environments.

New York State has been actively engaged in increasing employment outcomes for persons with disabilities; policy and funding support competitive employment. New York State leads the nation in Ticket-to-Work participants and has a Medicaid Buy-in enrollment of over 4000 individuals. Collaborative efforts have substantially increased physical & programmatic accessibility of the New York State Workforce Development One-Stop System. There has been a consistent increase in training programs and supported employment to help people with disabilities move into competitive employment and contribute to the tax base. The ability to obtain employment that allows consumers to maintain public health benefits or comparable benefits packages from employers remains a critical issue. Analysis of necessary skills to meet employer needs in the changing economic climate is ongoing.

While strong State and federal policies are encouraging employment of individuals with disabilities, the rate of employment amongst adults with disabilities is significantly lower than the rate of employment for the general public and, recently, the gap has increased. The current employment rate for adults with disabilities stands at about 34% as compared to about 95% for the general population; thus, the relative rate of unemployment for people with developmental disabilities is significantly higher than the general public. In some areas, individuals with more severe disabilities remain in segregated employment settings. With currently low unemployment, agency initiatives foster competitive employment targeted toward reducing this discrepancy.

HOUSING

The needs of adults with developmental disabilities are met by a network of State and non-profit provider agencies. This network provides a full range of residential opportunities - intermediate care facilities, community residences, family care, home sharing, independent living with appropriate supports, and home ownership. As the system moves to a community system with reliance on the non-profit sector for development of community residential options, there is still a recognized need for capacity to serve a limited core of individuals with special needs who currently reside in developmental centers.

In recent years, New York State has reduced its developmental center census through carefully targeted naturally occurring vacancies in existing community residential options. In recent years, however, the State has made a commitment, through NYS CARES, to develop additional residential opportunities with enhancements to other service offerings. The purpose of NYS CARES is to develop residential situations built on individualized services that include greater consumer choice and flexibility consistent with the Home and Community Based Services waiver program.

Much of recent housing development has relied on identification of other sources of public and private funding. Collaboration with the Division of Housing and Community Renewal (DHCR) and Housing and Urban Development (HUD) along with Home of Your Own (HOYO) efforts to access private mortgage funds have been fruitful in making additional low income housing units and development dollars available. DHCR continues to chair the Governor's Housing Task Force for Persons with Special Needs.

Self-Advocates have urged the system to reduce its reliance on large community-based congregate settings. Consumers and family members have consistently expressed the need for more housing options, flexibility, choice, and in-home service options. In attempting to meet demand, it has become evident that a complementary step is needed that will improve individual ability to keep these newer, smaller, more individualized living arrangements. Increasing financial literacy, home maintenance and relationships with mortgagors and landlords are an essential adjunct to "home of your own" effective efforts.

COMMUNITY SERVICES

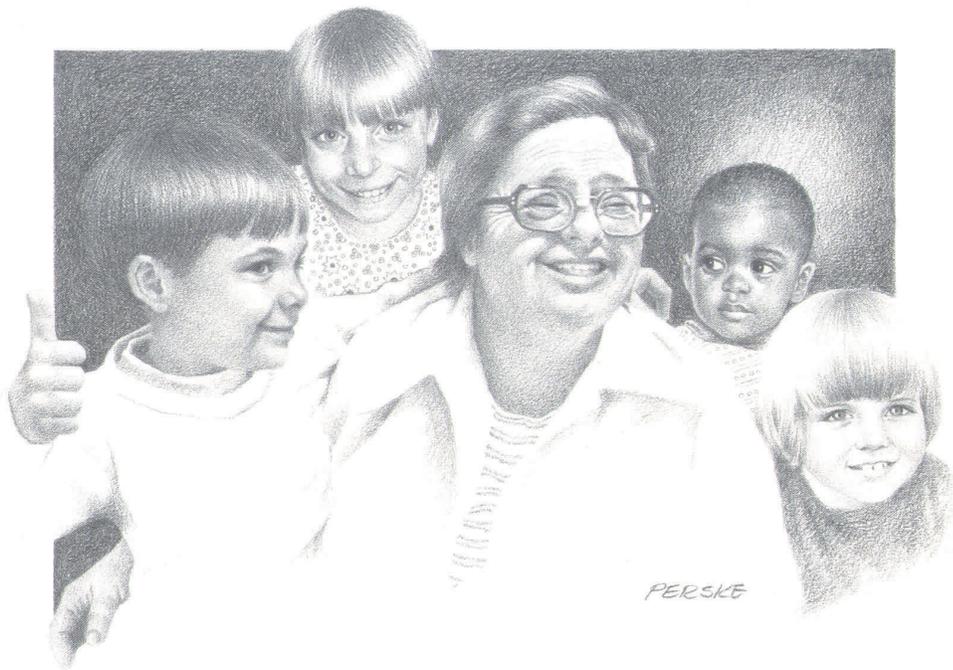
In New York State, community supports include many service areas - individual and family supports, personal assistance, day programs, recreation, technology and transportation that are overseen by different State agencies:

- Office of Mental Retardation and Developmental Disabilities (OMRDD) administers the individual and family support programs that allow families to keep their family members living at home and individuals to live independently.
- OMRDD also oversees day service programs that include habilitation and vocational skills training, social community activities, and job-related activities.
- New York State Options for Persons Through Services (OPTS) at OMRDD provides another venue for development of more individualized ways of meeting service and support needs.
- Personal assistance programs, including consumer directed models, are the purview of the State Department of Health and the local social services units.
- Recreation is typically overseen by localities through schools, youth and parks programs. New York State also has a large public park system and International Paper has built the first fully accessible park for individuals with disabilities which is located in the Adirondack Mountain region of New York State.
- The Technology Related Assistance for Individuals with Disabilities program in the Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD) is the locus of efforts to improve policy on and access to assistive technology.
- The Department of Transportation (DOT) provides oversight and funding for locally operated transportation systems including bus, subway, commuter rail, and para-transit services.

COMMUNITY SERVICES (continued...)

A number of policy initiatives, including development of a new Nursing Home Transition and Diversion Medicaid waiver, are underway to transition or divert individuals from institutional placement into supportive community alternatives. Early efforts are paving the way for more large-scale future efforts. These efforts rely on and compliment aging-in-place initiatives.

Over many years, the developmental disabilities service system has successfully increased its emphasis on providing services in the community. More recently, efforts have been directed to improving capacity of generic community services providers to include individuals with developmental disabilities in existing programs; these efforts are only beginning to show improvements with much more work to be done. A necessary adjunct, however, is improving the perception of individuals with developmental disabilities amongst the general population.



SELF-ADVOCACY AND QUALITY ASSURANCE

Ongoing collaboration to promote self-advocacy and self-determination, as well as ensure quality continues with the Protection and Advocacy program in the New York State Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD), The Office of Mental Retardation and Developmental Disabilities (OMRDD), and the Division of Human Rights. Each of these agencies has a designated role in assuring the rights of individuals with disabilities at the systems level and the quality of available services and support.

DDPC has taken the lead, however, on consumer empowerment initiatives with significant efforts in self-advocacy, citizen advocacy, Partners in Policy Making Training, Independent Parent Advocacy Networks, and self-determination. DDPC is currently working to establish an advocacy resource network to assist advocates and advocacy organizations to better meet the needs of families. This is the culminating step based on over a decade of work in this arena.

The Self-Advocacy Association of NYS (SANYS) has grown and thrived over the years and currently has an annual budget of \$1.3 million from grants and membership dues. Regional self-advocacy associations and varied self-advocacy initiatives continue to thrive with a focus on self-determination and self-direction for all consumers. Self-advocates are involved in finding solutions to transportation, legal, medical, and employment problems and to improving community attitudes. As this organization has grown and prospered, it has become a partner in developmental disabilities policy making. Concomitantly, an internship program has been developed by OMRDD which provides paid experience work experiences at the program and policy levels.

State level planning for the Alliance for Full Participation highlighted the need for concerted disability awareness and sensitivity effort. Communities need assistance in accepting and supporting the community participation and membership of individuals with developmental disabilities.



COMMUNITY SERVICES AND OPPORTUNITIES

A recent federal Centers for Medicare & Medicaid Services review of the NYS Home and Community Based Waiver Program found it to be a well managed community support system where participants benefit from well designed and executed supports and services that maintain their individuality and inclusion in the community. The program “has achieved a level of program implementation that meets and exceeds the stipulations in the waiver” with “no systemic problems that require corrective action.”

The OMRDD Division of Quality Assurance (DQA) has an extensive survey process, which assesses the performance of its service providers in relation to established indicators of outcomes for individuals, based on regulatory requirements. Analysis of survey data for the period 4/01 - 3/06 identified five broad areas cited most often as needing improvement. These are: cleaning, general maintenance and repair of residences; access to and monitoring of health care; consistent receipt of needed treatment and services; staff training; and the investigation of incidents. OMRDD, in concert with the statewide provider organizations, instituted an ongoing series of regional provider training sessions, as well as its extensive catalog of staff training offerings and on-line learning opportunities, to foster improvement in these and all key areas of services and supports.

The Executive Budget has a major focus on quality in care and services, specifically recruitment and retention of direct support workers and re-deployment of existing staff. Other initiatives include a proposed enhancement of the Medicaid trend factor that will allow providers to increase the average direct support worker salary and fringe benefit package; an incentive program aimed at staff development and retention; and statewide expansion of the award-winning Everyday Heroes worker recognition and training program.

Assistive technology (AT) was recently defined in litigation and is gradually becoming more available, although funding for both AT and durable medical equipment is an ongoing challenge. This is not inconsistent with the current concern over the impact of potential changes in Medicaid at the state and federal levels that may cause reductions or limitations in developmental disabilities rehabilitation and long-term care services.

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

There has been a long-standing recognition that individuals with developmental disabilities and their families from ethnic or racial minority groups should be better served by the service delivery system. The extreme 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

Individuals from the following groups indicate that the quantity and skills of the workforce are a significant deterrent to receipt of services. Additional perceived barriers include: workforce turnover and worker 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.

Specific concerns have been identified for the following groups:

- **Group:**

Children and adults with developmental disabilities requiring services from multiple service systems

- **Barrier:**

Individuals with any kind of dual diagnosis/multiple service system needs report difficulty in getting appropriate services and cross system coordination.

UNSERVED AND UNDERSERVED GROUPS

General Barriers

(Continued...)

- **Group:**

Children and adults with developmental disabilities and challenging behaviors.

- **Barrier:**

Families of individuals with challenging behaviors report that these behaviors deter access to needed services and suspension/delayed in service availability.

- **Group:**

Individuals with functional disabilities, other than cognitive disabilities, who may not be eligible for DD services but may benefit from supports.

- **Barrier:**

Individuals with Significant Learning Disability (SLD), Asperger's Syndrome, Cerebral Palsy (CP), Epilepsy, Traumatic Brain Injury (TBI) and Attention Deficit Hyperactivity Disorder (ADHD) but no intellectual disability note refusal of services despite restricted functional capacity.

- **Group:**

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

- **Barrier:**

Individuals from rural, urban, isolated and congested areas report transportation/distance as barriers to receipt of services and worker availability.

**New York State
Developmental Disabilities
Planning Council**

***Goals
and
Objectives
by
Areas of Emphasis***

State Plan

2007-2011

RATIONALE FOR GOAL SELECTION

The DDPC has chosen to work under twelve 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 twelve targeted areas, DDPC has had long term agendas in the areas of employment, homes, transportation, self-determination, leadership and networking, and un/under-served populations. Children's services, health, preventive/protective services, workforce, and community participation, while not new to the DDPC, have moved in expanded/different directions based on public input. The final goal falls under cross cutting issues and allows investigation or capacity building in emerging areas of concern. A comprehensive background paper has been developed for each of the twelve areas 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.

Long Term Commitment

DDPC initiated the state plan development process by looking carefully at its current and past work to identify efforts needed to get to the desired point in each area of concern. Six areas were identified for continued work.

Over decades, DDPC has worked on specialized employment, housing and transportation to identify barriers to services, demonstrate new approaches, and in the instance of housing, build capacity to access private and public development dollars. Work in employment and housing have been very successful; but more limited in transportation due to the expense of such services. Public input has identified transportation as a critical adjunct to almost all other services and support needs and crucial to living and working in the community. Increasingly, the emphasis of work has pointed to a need for capacity building in these generic systems using the specialized systems in a supportive role. Thus goals and objectives for 2007-2011 are focused to:

- increase capacity in the generic competitive employment system with an emphasis on youth and customized employment;
- help individuals with developmental disabilities who have obtained homes in the community to keep and maintain those homes; and
- share best practices in transportation and encourage their replication.

RATIONALE FOR GOAL SELECTION (CONTINUED...)

A long-term commitment to self-determination is being translated into fundable self-determined and self-directed living. Systemic capacity is increasing: person-centered planning is being adopted; people are moving from institutional to less restrictive community settings; choice and flexibility are achievable. Work with self-advocates and the service system has resulted in a self-determination infrastructure ready for refinement and expansion to offer a self-directed option with administrative support for those individuals who prefer less administrative responsibility. However, it is a hard system to negotiate and it takes “superhero” individuals and families to make it work. The next commitment is to building provider community capacity and increasing ease of use.

Similarly, DDPC has spent more than a decade developing leadership skills amongst consumers and building advocacy capacity and resources ourselves and in its partnership with others. With capacity building and demonstration projects, DDPC has come to a point where all of that work is ready to be brought together into a sustainable statewide advocacy resource network during FFY 2007-2011.

Work with under-served populations has highlighted the importance of continued effort. In particular, individuals with behavior challenges and/or needing services from more than one service system, individuals and their families from geographically or culturally diverse backgrounds, individuals who are not eligible for state services but would benefit from supports continue to point out that they are not well-served. There have been significant successes in building service system capacity in the last three decades.

While strategies are developed consistent with the needs of the focal group, continuous attention to identification of these groups and the barriers to services and support they experience is essential – it is also supported by public input.



RATIONALE FOR GOAL SELECTION

(CONTINUED...)

Public Input

Along with information from the Protection & Advocacy Program and the University Centers for Excellence, DDPC engaged in state-level planning for the Alliance for Full Participation (AFP) and sought information using an individual/family survey (paper and on-line), a provider survey (paper and online), and priority setting focus groups at existing venues with grantees, partners, collaborators and, particularly, self-advocacy groups.

AFP state-level planning provided a collaborative agenda for leadership, self-determination, community participation, and quality assurance which is infused throughout the 2007-2011 DDPC State Plan.

Findings of the Individual and Family Survey were:

- Consumers and families were generally pleased with offerings but would like more information, greater availability of services and supports, ease in use, an emphasis on coordinated children's services, and less adversarial relationships and interactions;
- Identified as the most useful were service coordination, residential habilitation, services for children (including respite), family supports, legal & advocacy services, information on services and financing, appropriate educational services, recreation and socialization;
- Identified barriers were lack of information on services, financing and procedures, staff shortages and lack of trained personnel, confrontations with educators, bureaucratic and procedural difficulties, availability of community services/supports, service coordination and respite, and adequacy of healthcare; and
- Desired are more information and trained staff, less bureaucratic procedures, changes to education system; transportation to work and socialize, affordable and accessible housing, social and leisure time activities, appropriate health care, respite, job opportunities and vocational training, advocacy groups and support circles.

RATIONALE FOR GOAL SELECTION

(CONTINUED...)

Findings from the Provider Survey were:

- DDPC should look at ways of increasing quantity and quality of staff, reducing procedural difficulties, increasing access to needed information and ease of interactions;
- Identified challenges include difficulty in providing service coordination and in-home services to meet the demand; service and support availability and/or eligibility barriers; procedural difficulties; access to information; inadequate financing; consistency in staff and finding dedicated, trained personnel;
- Worker salaries, benefits and training; reducing procedural difficulties and easier access to reliable information; making self-determination actually work for people; and finding additional funding and sources of support are needed to make work more rewarding; and
- More staff and housing opportunities, increased financial support and budgets, greater capacity for self-determination and community participation, and ease in interactions within and across systems are needed for the system to be more responsive.

Findings from the Priority Setting Focus Groups were:

- DDPC has chosen areas of greatest need and highest likelihood of success;
- Workforce and transportation are critical to success in all areas;
- Increased emphasis on cultural competence and multi-lingualism is needed;
- Continued attention to aging (individuals & caregivers) and health care are crucial;
- Success should be measured in terms of quality of life and identification of promising practices; and
- Self-Advocates and Service Coordinators are critical partners.

RATIONALE FOR GOAL SELECTION

(CONTINUED...)

This information was used to refine the six areas where DDPC has a long term commitment, as well as to define and refine agendas in the areas of children's services, health, preventive/protective services, workforce, and community participation and development:

- DDPC continues to promote provision of services and supports needed to assure age-appropriate educational, social, emotional and developmental growth. Information from various sources has pointed to increasingly adversarial relationships between families and educators and delays in fully implementing existing policies on inclusion. Thus, increased attention will be directed to building capacity to function within existing state policies on inclusion, increasing effective communication and cross-systems coordination, and inclusive post-secondary options;
- All areas of health care have been identified as inadequate by consumers, providers, and collaborators. Thus, DDPC has significantly increased its focus on quantity, quality and ease of use of health care services for individuals with developmental disabilities. This includes work in the areas of access to care, health and wellness, oral health, health care transitions, worker education and disability prevention;
- As more individuals with developmental disabilities are living in the community, support systems are needed to assure their safety and well-being. Information from protective services and recent disasters have pointed to the need for services and supports for foster care and adoptive families of children with disabilities, for families headed by parent (s) with developmental disabilities, prevention of domestic and other violence (s) involving individuals with developmental disabilities, and attention to individuals with disabilities in the emergency preparedness and response arenas;
- Consumers, providers and collaborators have all noted the importance of the workforce in providing services and supports to individuals and families. Also, agencies indicate that they are conceptually in agreement with self-determination and community participation but need help adjusting organizations and practice to be more responsive. Thus, DDPC will work on these areas, as well as on increasing consumer participation in that workforce; and

RATIONALE FOR GOAL SELECTION

(CONTINUED...)

- Attitudinal and transportation barriers, financial considerations, and great diversity have made it difficult for individuals with developmental disabilities and their families to fully participate in community life. Clearly, significant work needs to be done for individuals to be “in the community” as well as “of the community” and to build communities around individuals who may need additional assistance and supports for community membership. Thus, community development, and participation through disability awareness, sensitivity, social, faith-based and recreational activities, access to assistive technology and building capacity for aging, and end-of-life care will be undertaken.



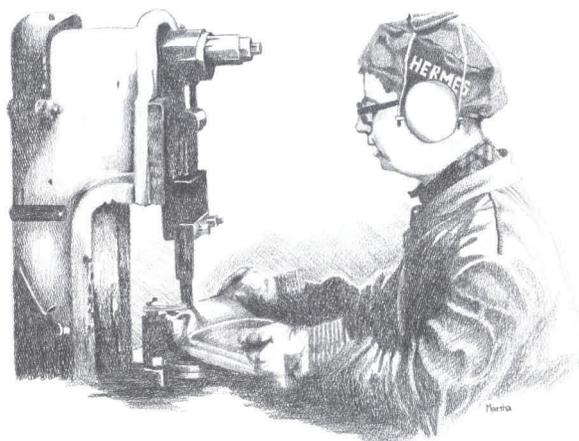
AREA OF EMPHASIS: EMPLOYMENT

Goal & Objective Statements

- **Goal EM1:** Improve the relative parity of people with developmental disabilities when compared to the employment levels within the general public.

Specific Objectives:

- **EM 1.1** - By 2011, four (4) additional customized employment services or resources will be available to assist individuals with developmental disabilities obtain and maintain their employment.
- **EM 1.2** - By 2011, DDPC will address policy, practice or funding barriers that will result in 500 young adults with developmental disabilities obtaining employment and receiving services and supports needed to maintain employment.
- **EM 1.3** - By 2011, DDPC will have engaged in four (4) activities that improve the capacity of generic employment services to assist individuals with developmental disabilities to obtain and maintain employment.



***AREA OF EMPHASIS:
EDUCATION, EARLY INTERVENTION
AND CHILDREN'S SERVICES***

Goal & Objective Statements

- **Goal ED1:** Enhance programmatic responsiveness to maximize the inclusion of children with developmental disabilities in education, early intervention, and child care services as well as community life.

Specific Objectives:

- **ED 1.1** - By 2011, DDPC will address policy, practice or funding barriers that will result in 60 programs for child care and/or school-aged children becoming more inclusive.
- **ED 1.2** - By 2011, four (4) cross- systems coordination initiatives will improve generic services and supports and use of them for children with disabilities and their families/caregivers.
- **ED 1.3** - By 2011, 4-6 activities will be undertaken that will affect students with developmental disabilities who are able to and desire to attend programs at colleges (or other post-secondary options) with appropriate supports.



AREA OF EMPHASIS:

HEALTH

Goal & Objective Statements

- **Goal HE1:** Ensure access to and expand appropriate and quality health promotion, wellness, medical, oral and health care services available to children and adults with developmental disabilities.

Specific Objectives:

- **HE 1.1** - By 2011, DDPC will have engaged in six (6) activities which increase access to appropriate and effective health care for children and adults with developmental disabilities.
- **HE 1.2** - By 2011, DDPC will have identified and implemented three (3) ways of increasing access to oral health care for individuals with developmental disabilities or decreasing the disparity in care.
- **HE 1.3** - By 2011, DDPC will have engaged in ten (10) disability prevention activities, including activities to prevent secondary conditions.
- **HE 1.4** - By 2011, a sustainable institute on health care transition will provide assistance to individuals, families/caregivers, and providers.
- **HE 1.5** - By 2011, a network of health and wellness programs and resources will be available to provide assistance statewide to individuals with developmental disabilities, their families, caregivers, service coordinators and other service providers.
- **HE 1.6** - By 2011, training for health-related personnel and providers, primary care medical residents and other health care providers and support personnel will routinely include disability content and direct experiences with children and adults with developmental disabilities and their families/caregivers.

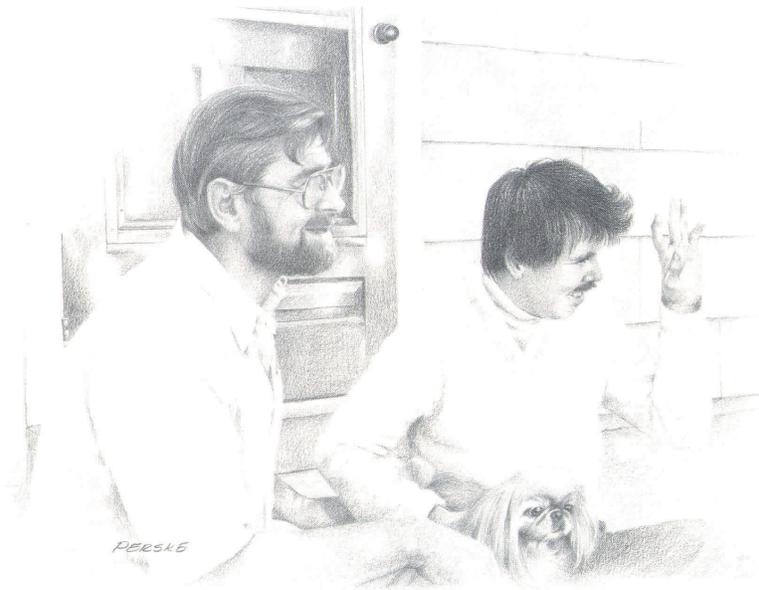
AREA OF EMPHASIS: HOMES

Goal & Objective Statements

- **Goal HO1:** Increase housing and support options available to adults with developmental disabilities and their families.

Specific Objectives:

- **HO 1.1** - By 2011, DDPC will have engaged in five (5) initiatives which increase affordable and accessible housing options.
- **HO 1.2** - By 2011, DDPC will have engaged in six (6) initiatives which help people with developmental disabilities keep and maintain their homes and/or preferred housing arrangement.



AREA OF EMPHASIS: TRANSPORTATION

Goal & Objective Statements

- **Goal TR1:** Increase transportation options for individuals with developmental disabilities that open participation in employment & community life.

Specific Objectives:

- **TR 1.1** - By 2011, DDPC will have identified, for potential replication, four (4) models for increasing transportation options, both fixed route and individualized/on-demand for people with developmental disabilities.
- **TR 1.2** - By 2011, identify and address at least two (2) policy barriers to transportation for individuals with developmental disabilities that are amenable to change.



***AREA OF EMPHASIS:
QUALITY ASSURANCE - PROTECTIVE
& PREVENTIVE SERVICES***

Goal & Objective Statements

- **Goal:** Protect and support individuals with developmental disabilities in family and community settings.

Specific Objectives:

- **QA 1.1** - By 2011, three (3) policy, practice or funding barriers will be resolved resulting in more responsive services/supports for children with developmental disabilities in foster care or adoptive settings and their families/caregivers.
- **QA 1.2** - By 2011, three (3) policy or practice barriers to maintaining families headed by persons with developmental disabilities will be effectively resolved.
- **QA 1.3** - By 2011, three (3) policy or practice barriers related to abuse prevention for individuals with developmental disabilities will be resolved.
- **QA 1.4** - By 2011, three (3) disability-related policy or practice barriers in emergency preparedness planning will be addressed.



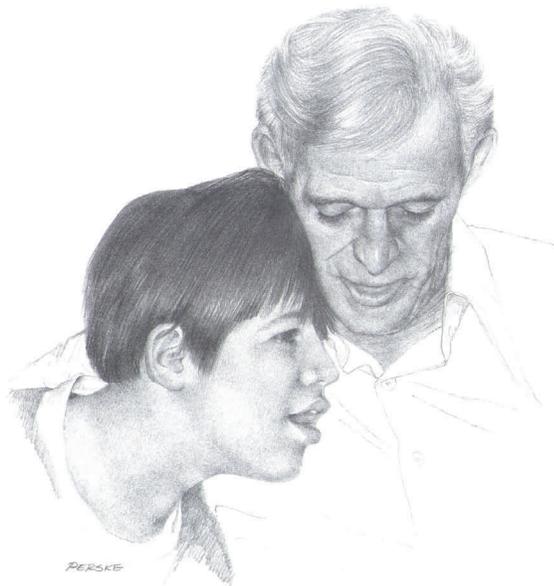
***AREA OF EMPHASIS:
QUALITY ASSURANCE - ADVOCACY
& LEADERSHIP***

Goal & Objective Statements

- **Goal QA2:** Develop strong cohesive developmental disabilities advocacy networking and leadership in New York State.

Specific Objectives:

- **QA 2.1** - By 2011, a statewide advocacy resource network will be established and responding to the needs of its members.
- **QA 2.2** - By 2011, a statewide advocacy resource network will be established and responding to the needs of its members.
- **QA 2.3** - By 2011, four (4) models for increasing the number of disability advocates will be demonstrated and functioning.



AREA OF EMPHASIS: QUALITY ASSURANCE - WORKFORCE

Goal & Objective Statements

- **Goal QA3:** Increase the quantity, quality and competence of people working in the developmental disabilities workforce.

Specific Objectives:

- **QA 3.1** - By 2011, three (3) approaches to increased presence of individuals with developmental disabilities and their family members in the workforce will be demonstrated.
- **QA 3.2** - By 2011, four (4) additional methods of increasing the quantity, competence and stability of the developmental disabilities workforce will be identified, demonstrated, and replicated.
- **QA 3.3** - By 2011, four (4) methods of increasing organizational and administrative capacity for providing self-directed/self-determined approaches to service/support provision will be identified, piloted and replicated.



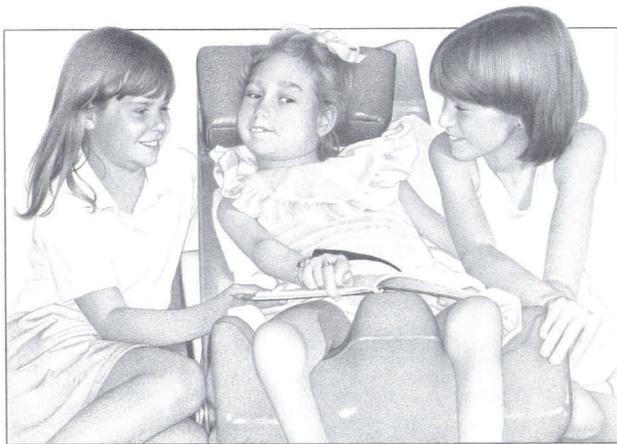
***AREA OF EMPHASIS:
QUALITY ASSURANCE -
SELF-DETERMINATION***

Goal & Objective Statements

- **Goal QA4:** Promote and support individuals to lead self-determined lives with valued community membership.

Specific Objectives:

- **QA 4.1** - By 2011, four (4) service systems will increase person-centered planning capacity and one (1) additional service systems will have adopted person-centered approaches to transition planning.
- **QA 4.2** - By 2011, self-determination programs and supports, including a self-direction option, will be established in NYS and evaluated for effectiveness and satisfaction.
- **QA 4.3** - By 2011, capacity for choice and flexibility in community-based services and supports will be increased resulting in a minimum of 200 individuals transitioned to less restrictive settings or diverted from more restrictive settings.



***AREA OF EMPHASIS:
COMMUNITY SERVICES -
UN / UNDERSERVED POPULATIONS***

Goal & Objective Statements

- **Goal CS1:** Children and adults with developmental disabilities from un / underserved populations have equitable & appropriate access to culturally-sensitive community and specialty services.

Specific Objectives:

- **CS 1.1** - By 2011, DDPC will undertake five (5) initiatives focused on community inclusion and access to needed services and supports for individuals with developmental disabilities and their families/caregivers from under-served populations.
- **CS 1.2** - By 2011, three (3) strategies for addressing behavior challenges in children and/or adults with developmental disabilities will be identified and implemented.
- **CS 1.3** - By 2011, five (5) training and technical assistance initiatives will be undertaken and evaluated for workers serving underserved populations.



AREA OF EMPHASIS:
COMMUNITY SUPPORTS -
COMMUNITY PARTICIPATION

Goal & Objective Statements

- **Goal CS2:** Improve quality of life and community participation for children and adults with developmental disabilities, including participation in recreational, social and leisure activities.

Specific Objectives:

- **CS 2.1** – By 2011, three (3) policy, practice or systems change methods for promoting social inclusion and community participation of individuals with developmental disabilities will be identified, piloted, refined and/or evaluated.
- **CS 2.2** – Annually undertake, in collaboration with the Technology Related assistance to Individuals with Disabilities Project (TRAID), one initiative focused on increasing access to and affordability of assistive technology and durable medical equipment.
- **CS 2.3** – By 2011, DDPC will engage in at least 3 activities to promote inclusion of individuals with disabilities in religious communities of their choice.
- **CS 2.4** – Engage in one (1) focused disability awareness/sensitivity activity annually which encourages greater community participation of individuals with disabilities.
- **CS 2.5** – By 2011, engage in four (4) activities which improve capacity to support individuals with developmental disabilities who are aging so that they can remain in their home and community.

***AREA OF EMPHASIS:
CROSS CUTTING -
EMERGING ISSUES
& COMMUNITY EDUCATION***

Goal & Objective Statements

- **Goal CC1:** DDPC activities that impact on one or more Areas of Emphasis.

Specific Objectives:

- **CC 1.1** - Annually investigate at least one emerging issue that is not necessarily disability- specific but appears to have a significant impact on children and/or adults with developmental disabilities, and determine a role for DDPC.
- **CC 1.2** - Initiate at least one capacity-building or information dissemination activity annually that responds to an area of consumer and provider concern.
- **CC 1.3** - Support conference and workshop attendance of 2000 consumers annually to obtain information essential to informed decision making.
- **CC 1.4** - By 2011, the DDPC monthly E-Bulletin will have 3000 subscribers.



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

Grant Funding Guidelines

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

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

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

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

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

New York State Developmental Disabilities Planning Council

155 Washington Avenue—Second Floor

Albany, NY 12210

518-486-7505

- or -

Email: ddpc@ddpc.state.ny.us

- or, available online at -

Website: www.ddpc.state.ny.us



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

How a Concept Becomes a Grant

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

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



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

Unsolicited Proposals

Purpose

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

Policy

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

Procedure

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

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



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

Request for Proposal (RFP) Process

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

- The DDPC defines a funding opportunity and sets aside sufficient funds to support a targeted initiative consistent with objectives in the current DDPC State Plan.
- Based on the needs identified by a workgroup, an RFP is authorized by the DDPC and is developed by DDPC Members, staff and key system stakeholders. Stakeholders who might want to apply for such an opportunity are precluded from working with the workgroup and/or on the RFP.
- The RFP is sent out to a targeted mailing list of agencies that meet the eligibility criteria for the specific RFP. The RFP is also posted in the New York State Register and on the DDPC website to ensure access to the RFP. Key partners are encouraged to disseminate the RFP and provide web-links to interested and appropriate 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: _____

SOCIAL SECURITY #: _____

**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

155 Washington Avenue / Second Floor—Albany, NY 12210

1-800-395-3372

George E. Fertal, Sr., Chairperson

Sheila M. Carey, Executive Director

Rose Marie Toscano, Vice-Chair

Comments Section

NYS Developmental Disabilities Planning Council State Plan 2007-2011

- *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, Ph.D., Deputy Executive Director
NYS DDPC**

**155 Washington Avenue / Second Floor
Albany, NY 12210**

Email: ddpc@ddpc.state.ny.us

Fax: (518)402-3505



**New York State
Developmental Disabilities
Planning Council**

**155 Washington Avenue / Second Floor
Albany, NY 12210**

**1-800-395-DDPC (3372)
Toll Free Voice and TDD/TTY
(518) 486-7505 (VOICE)
(518) 402-3503 (FAX)**

Website: www.ddpc.state.ny.us

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