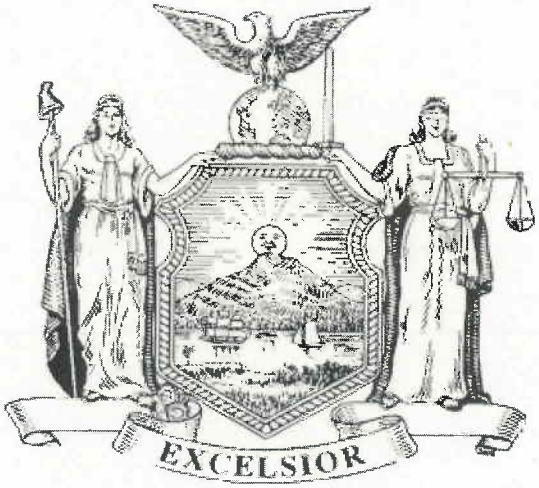


Creating a World of Change

2002-2006

State Plan

For the

New York State Developmental Disabilities Planning Council

George E. Pataki Governor

Sheila M. Carey
Executive Director

Michael J. Mackin
Chairperson

Duncan Whiteside
Vice-Chairperson

Creating a World of Change

2002-2006

State Plan

For the

New York State Developmental Disabilities Planning Council

George E. Pataki, Governor

Michael J. Mackin, ***Chairperson***

Sheila M. Carey, ***Executive Director***

Submitted to:

Administration on Developmental Disabilities

On

August 15th, 2001

Table of Contents

- **Preface** — Page 1
- **Introduction** — Page 2
- **Developmental Disabilities Planning Council** — Pages 3—4
  - General Statement of Philosophy
  - Organization
- **Council Membership** — Pages 5—6
  - Consumer Members
  - Non-Governmental Agency Members
  - University Centers for Excellence Members
  - State Agency Members
- **DDPC Staff** — Page 7
- **The Plan Development Process** — Pages 8—10
  - Review and Analysis of Current DDPC Efforts
  - Review and Analysis of Local, State, and Federal Documents
  - Review and Analysis of Specific Information Gathered
    - Individual and Family Perspective
    - Provider and Professional Perspective
    - Policy Makers Perspective
- **The New York State Service System** — Pages 11—14
  - Economic Factors
  - Social Factors
  - Political Factors
  - Litigative Factors
- **Specific Features** — Pages 15—22
  - Education and Child Development
  - Healthcare
  - Employment
  - Housing
  - Community Services
  - Self-Advocacy and Quality Assurance
  - Unserved and Undeserved Groups
    - General Barriers
    - Barriers Relating to Specific Groups
- **Objectives by Area of Emphasis** — Pages 23—33
  - Employment
  - Homes
  - Health
  - Education and Early Intervention
  - Childcare
  - Transportation
  - Recreation
  - Other Community Support
  - Quality Assurance
  - Cross Cutting
- **Council Membership Application** — Pages 34—35
- **Comments Section** — Page 36

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 will be effective October 1, 2001, and cover federal fiscal years 2002, 2003 and 2004, 2005 and 2006 ending September 30th, 2006.

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, and 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 to be fully involved in the design, implementation, evaluation, and quality assurance aspects of the programs that serve their needs. A primary avenue for attaining this end 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 2002-2006 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 at 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 hard 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 consideration, the 2002-2006 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.

~

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.*

~

Organization

The DDPC is composed of 36 members who have been appointed by the Governor. Federal law requires that at least 60 percent of the 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. All DDPC members are appointed by the Governor.

The Chairperson of the DDPC is appointed by the Governor from the membership. The current DDPC Chairperson and Executive Director are listed below:

Chairperson:

Michael J. Mackin
Camp Venture, Inc.
PO Box 402
Nanuet, NY 10954
Telephone: (845) 365-1316

Executive Director:

Sheila M. Carey
NYS Developmental Disabilities Planning Council
155 Washington Avenue / Second Floor
Albany, NY 12210
Telephone: (518) 486-7505
1-800-395-3372

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.

The DDPC has a full-time staff of eighteen who are solely responsible for assisting the DDPC in carrying out its duties and functions under the direction of the Executive Director. This document contains: a) a listing of the consumer and agency members of the DDPC; and b) a listing of DDPC staff, including titles.

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, and other relevant state agencies to ensure interagency coordination of activities and to promote systemic change.

COUNCIL MEMBERSHIP

Consumer Members

Daniel M. Ajello, Esq.
Kermit Augustine
Adam Denenberg
Susann R. Durham
Virginia Ellis
George E. Fertal, Sr.
Kevin Kennedy
Barbara Levitz
Michael J. Mackin, DDPC Chairperson
Ann A. McDonnell
Reverend Dennis Meyer
Harold Monroe
James R. Muldoon, Esq.
Wendy P. Orzel
Raymond Ozarow
Elsa Peters
Patrick F. Reilly
Ann L. Scherff
Sue A. Thomas Sehl
Rose Marie Toscano

Non-Governmental Agency Members

Pamela B. Conford, M.S., C.S.W.
Duncan Whiteside, DDPC Vice-Chairperson

University Centers for Excellence Members

Ansley Bacon, Ph.D.
Philip W. Davidson, Ph.D.
Herbert J. Cohen, M.D.

State Agency Members

Honorable Joseph H. Boardman
Commissioner
NYS Department of Transportation

Honorable Glenn Goord
Commissioner
NYS Department of Corrections

Honorable Thomas Maul
Commissioner
NYS Office of Mental Retardation and Developmental Disabilities

Honorable Richard P. Mills
Commissioner
NYS Education Department

Honorable Antonia C. Novello, M.D., M.P.H., Ph.D.
Commissioner
NYS Department of Health

Honorable Gary O'Brien
Chairman
NYS Commission on Quality of Care for the Mentally Disabled

Honorable Patricia Pine, Ph.D.
Director
NYS Office for the Aging

Honorable Judith A. Colagero
Commissioner
NYS Division of Housing & Community Renewal

Honorable Richard Warrender
State Advocate
NYS Office of Advocate for Persons with Disabilities

Honorable Brian J. Wing
Commissioner
NYS Office of Temporary and Disabilities Assistance

DDPC STAFF

Sheila M. Carey, Executive Director

Anna F. Lobosco, Ph.D., Deputy Executive Director

Nicolas Rose, D.D. Program Planner II

Robin Worobey, D.D. Program Planner II

James Huben, D.D. Program Planner II

Thomas F. Lee, Public Information Officer

Russell Wise, Associate Budget Analyst

Thomas Meyers, Computer Programmer / Analyst

Donna Breslin, Computer Programmer / Analyst

Lois Goodwill, Executive Secretary

Eileen S. Grant, Special Assistant

Edward Vandercar, Program Research Specialist II

Sharon Winchester, Program Research Specialist II

Kerry Wiley, Research Analyst

Mary Sampson, Secretary I

Elaine Weiss, Secretary I

Nathaniel Douglas, Keyboard Specialist

Alex Harrington, 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.

THE PLAN DEVELOPMENT PROCESS

In order to develop the 2002-2006 DDPC State Plan, the full Council membership reviewed and analyzed a wide variety of new and existing information. This information came from the following sources:

- current DDPC efforts;
- local, state and federal documents; and
- information gathered specifically to support plan development.

The DDPC sought feedback and information from a range of stakeholders that had an impact on the entire service delivery process.

Review and Analysis of Current DDPC Efforts

On an ongoing basis, the DDPC reviews activities and progress toward meeting the goals and objectives included in its current State Plan. The DDPC staff, the three standing committees of the DDPC, the DDPC Consumer Caucus and, occasionally, topical work groups review the status of current activities and present that information at the quarterly meetings of the DDPC. Progress toward meeting stated goals and objectives is reviewed in light of lessons learned and by considering new information to determine need to alter activities in order to meet stated goals and objectives, as well as to determine needs for amendments to the State Plan.

Each of the standing committees is charged with implementing and evaluating a designated section of the State Plan, with the Consumer Caucus providing a forum for consumer input, and the Executive Committee ensuring oversight and coordination of the overall planning, review, implementation, and evaluation processes. Findings and recommendations are reviewed by the DDPC for action and approval.

Review and Analysis of Local, State, and Federal Documents

DDPC routinely reviews the plans, budgets and policy documents prepared by other state agencies and, where appropriate, their regional counterparts. In addition, the plans and annual reports of the State's three University Centers for Excellence (UCE) and the Protection and Advocacy Program (P&A) are also reviewed for pertinent information that will assist in the DDPC planning process. Significant findings from these sources are incorporated into the working knowledge of DDPC staff and passed to DDPC members for use in the planning process.

Review & Analysis of Specific Information Gathered

From the onset of the DDPC planning process, the need to gather specific, service related information from both consumers, providers, and policymakers was recognized. A series of information gathering activities was devised and implemented. A description of these information gathering activities follows.

Individual and Family Perspective

The DDPC gathered information from individuals with developmental disabilities and their families. Individuals with developmental disabilities, parents, family members, care givers, guardians, friends, advocates, and others were asked to comment on their experiences with the service system (both positive and negative). People were also asked to identify barriers which prevented or impeded them from getting needed assistance, types of assistance which had been the most helpful, and directions the DDPC should be moving in.

The DDPC information gathering activities included:

- Public forums in collaboration with DDPC grantees;
- Written comments solicited through a variety of avenue, including use of media, electronic bulletin boards, consumer groups, training sessions, and the assistance of provider agencies;
- Focus groups; and
- Guided discussions with regional self-advocacy groups.

Provider and Professional Perspective

The DDPC also gathered information from the provider community across New York State. Various groups of providers were asked to provide information for deliberation in the DDPC planning process.

Service providers were asked to provide comments on factors which had an impact on their ability to provide services, supports, and assistance to children and adults with developmental disabilities and their families. They were asked to comment on why they worked in the developmental disabilities service delivery system, the problems they experienced in serving individuals with developmental disabilities and their families, the causes of those problems, potential solutions to those problems (actual and hypothetical), and what role the DDPC should be taking in addressing the needs of the service system.

Information gathering activities were similar to and compatible with efforts to elicit comments from consumers, including:

- Soliciting comments via media, electronic bulletin boards, and provider groups;
- Including providers in public forum discussions;
- Holding round table discussions with clusters of DDPC grantees & workgroups; and
- Analysis of the contents of proposals in the recent DDPC Request for Ideas.

Policy Makers Perspective

- Meetings with agency heads & senior staff;
- Review of state agency planning documents and outcome, and established reports; and
- Solicitation of comments on proposed objectives and initiatives.

THE NEW YORK STATE SERVICE SYSTEM

ECONOMIC FACTORS

The New York State economy has been variable. Prior to September of 2001, the State was enjoying an unsustainable growth rate. Stock market corrections had slowed the rate of growth but moderate growth was expected through 2007. Regional variation was also noted due to relative strength of regionally based industry. Growth industries centered around the technology and biotechnology fields with significant growth expected in Long Island, New York City and Hudson Valley areas. Labor shortages were prevalent and unemployment was at its lowest point in recent history.

The collapse of the World Trade Center in NYC during September of 2001 had an immediate impact on the State economy. It is expected to have a significant and pervasive impact on the NYS policy and fiscal environment for the foreseeable future. NYS is currently in a recession and increases in unemployment rate have been noted. It is estimated that NYS will lose $9 billion in revenue prior to 2004 and the Chief Economist for NYS has predicted a long, slow recovery from this disaster.

Key economic factors affecting individuals with developmental disabilities are:

- Strong State and federal policies are encouraging employment of individuals with disabilities. However, increasing unemployment in the general population may negatively affect the already significantly higher rate of employment for individuals with disabilities;

- There has been increased availability of 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 persons with developmental disabilities to maintain public health benefits or comparable benefits packages from employers remains a critical issue; and

- Analysis of necessary skills to meet employer needs in this changing climate is ongoing.

In addition, New York State is developing its policy response to recent federal employment legislation (i.e. Workforce Incentives, Ticket to Work, Medicaid Buy-In).

SOCIAL FACTORS

People with developmental disabilities in New York State are affected by the concepts of community inclusion, self-advocacy/self-determination, cultural diversity/sensitivity, the changing structure of the family, and availability of technology. The concepts have helped to forge a new model and attitude in the design and delivery of services and supports for people with developmental disabilities.

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

- 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 this inclusion needs to be bolstered for real physical and programmatic inclusion to occur.

- New York State residents include individuals from 178 different countries, speaking 138 languages, 1/3 of whom are from minority groups, and over 3 million of whom are foreign born. This extreme diversity challenges efforts to meet service needs and to develop and maintain a culturally sensitive and responsive system.

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

- Finally, increased access to assistive and information technology has improved the quality of life for people with developmental disabilities. While policy supports greater access to such technology, funding and procedural issues need to be resolved for consumers to fully benefit.

POLITICAL FACTORS

Governor George E. Pataki's administration has continued efforts to lower taxes, create a more efficient, responsive government, and decrease dependence on government while creating new opportunities for greater independence and productivity. Legislative and budget proposals in the areas of welfare, healthcare and education reform, employment, housing, crime reduction, and transportation are intended to enhance the lives of all New Yorkers—including people with developmental disabilities and their families.

Governor Pataki has established the NYS-CARES initiative to eliminate the waiting list for adult residential services. It is anticipated that 8,100 individuals with developmental disabilities will have new community residential opportunities. Person-centered planning approaches are being employed to assure development of individualized services environments. NYS-CARES also provides for additional day services, service coordination and family supports.

NYS-CARES compliments State policies that favor institutional downsizing and community based resources. As developmental center closure has progressed, individuals remaining in these centers tend to have multiple and severe disabilities with significant medical and/or behavioral involvement that requires more intensive, specialized services that are harder to develop. The need for special programs for individuals with severe behaviors and/or involvement with the criminal justice system has also been increased.

In recent years, individuals with developmental disabilities and their families have called for stronger enforcement of State and federal laws and regulations prohibiting discrimination on the basis of disability. Training programs, such as Partners in Policymaking, have served to increase the involvement of consumers pro-actively involved in federal, state, and local policymaking. In addition, regional networks of independent parent advocates have been formed to provide ongoing technical assistance and serve as a clearinghouse of information for 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) over the past three years in the following areas: due process, the provision of written materials in appropriate alternate formats, and a variety of accessibility issues. For example, the New York State Protection and Advocacy network has played a critical role in pursuing litigation on a variety of disability issues:

- due process rights were established under the OMRDD Home and Community Based Services Medicaid Waiver;
- the New York City Commission on Human Rights was directed to provide audio copies of regulations for people who are blind;
- funding was secured for a motorized wheelchair which enhanced the independence of an individual who was non-ambulatory; and
- a college offered financial compensation to a man with epilepsy who was terminated from his student teaching position after he had had a seizure.

The array of services and supports available through the State Medicaid Program, including services provided under the Home and Community Based Waiver, will continue to be an important tool for meeting integration goals consistent with long-standing New York State policies supporting expansion of community-based services.

SPECIFIC FEATURES

EDUCATION & CHILD DEVELOPMENT

Educational services are primarily the responsibility of the New York State Education Department (SED). Collaborative efforts with the Office of Mental Retardation and Developmental Disabilities, the DDPC, the Office of Children and Family Services, and the Department of Health have strengthened the array of services for children with developmental disabilities and their families. These initiatives include:

- Early intervention (Health);
- Services for pre-school through college and adult education (Education);
- Childcare, foster care and adoption services (Children and Family Services);
- Family supports (OMRDD); and
- Public education and consumer training (DDPC).

In his 2000-2001 Budget, Governor Pataki proposed special education reforms that foster least restrictive environments, allocate enrollment funds, cover high-cost special needs funds for children moving into a school district, and expand/improve post-secondary transition for youth. At the same time the Board of Regents has applied higher learning standards that are cause for concern for students with developmental disabilities. 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 SED Office of Vocational and Educational Services for Individuals with Disabilities (VESID).

Families note:

- Geographic variation in quality of special education;
- More funding for inclusion should be available;
- Early intervention has assisted parents in getting services for their children with developmental disabilities;
- More information about early intervention is needed by pediatricians and parents, particularly regarding autism;
- All transitions across the life span are problematic and would benefit from integrating person-centered planning approaches in IEP development early in the child's education; and
- Difficulty in accessing childcare and recreation services, especially for children with challenging behaviors.

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 sound, cost-effective medical care and reducing incidence/negative outcomes of infectious disease. The DOH also administers the State Medicaid Program.

The New York State health care system is moving toward Mandatory Medicaid Managed Care. Managed care is voluntary for most people with developmental disabilities. DDPC has worked with DOH and OMRDD to inform consumers of their choices within Medicaid managed care. It is also anticipated that the Health Care Reform Act of 2000 will increase availability of health care services to people who are medically indigent— included are those with inadequate health insurance and rural residences. A campaign to increase availability of public health insurance for children is ongoing. Medicaid Buy-in proposals are currently under review.

DOH administers a wide range of health and wellness programs for all New Yorker's. Development of effective health and wellness programs for people with developmental disabilities however, is an area of key concern. Similarly, issues of prescription and payment for assistive technology led the DOH to partner with the Office of Advocate for Persons with Disabilities to develop augmentive communication and wheelchair mobility guidelines for practitioners.

Individuals requiring assistive technology note:

- Services for people with multiple and dual disabilities are difficult to obtain;
- Difficulty in obtaining/repairing DME and assistive technology;
- Healthcare practitioners often lack information/resources to adequately treat individuals with developmental disabilities;
- Shortage of Medicaid providers and lack of information are barriers to healthcare;
- Consumer-Directed Personal Assistance programs give consumers flexibility regarding personal assistance, recruitment, training, and scheduling of aides; and
- The Home and Community Based Services waiver program has improved access to 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 service 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/post-secondary levels are the SED 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. OMRDD maintains responsibility for adults with developmental disabilities employed in long-term sheltered work environments.

Recent employment data shows the relative rate of unemployment for people with developmental disabilities to be significantly higher than the general public. In some areas, individuals with more severe disabilities remain in segregated employment settings. With current variable unemployment rates, agency initiatives foster competitive employment targeted toward reducing the discrepancy in the unemployment rate for individuals with disabilities when compared to the general public. Welfare-to-work and work incentive activities should increase the number of people with developmental disabilities in the workforce.

In a similar vein, employers have indicated that their priority is to function efficiently in the business environment. They feel that human service approaches to employment of persons with developmental disabilities are not consistent with their goals. Thus, DDPC has planned more work with employers to identify more effective means of employing individuals with developmental disabilities while maintaining a focus on their business goals.

Consumers and families note:

- loss of critical health insurance and other entitlements due to employment;
- desire for competitive employment;
- need for more employment options (including full—and part-time options), transportation; and
- need for accommodation/support of people with severe disabilities.

HOUSING

The housing and support needs of adults with developmental disabilities are met through 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. The system increasingly relies on the non-profit sector for development of community residential options.

In recent years, New York State has reduced its developmental centers census through carefully utilizing naturally occurring vacancies in existing community residential options. In the last year, however, the State has made a commitment, through NYS-CARES, to develop over 5000 additional residential opportunities, and, with enhancements to other service offerings, provide residential opportunities built on individualized services environments that include greater consumer choice and flexibility consistent with the Home and Community Based Services waiver program.

Much of the recent housing development has relied on identification of other sources of public and private funding. Collaboration with the Department of Housing and Community Renewal and Housing and Urban Development along with ***Home of Your Own*** efforts to access private mortgage funds have been fruitful in making additional low income housing units and development dollars available. Home ownership efforts have been built on the principles of self-help, community partnerships, and future care planning.

Individuals and family members note a desire for more:

- housing options;
- flexibility;
- choice; and
- in-home service options.

COMMUNITY SERVICES

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

- 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.
- 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.
- The Technology Related Assistance for Individuals with Disabilities program in the Office of Advocate for Persons with Disabilities is the focus of efforts to improve access to assistive technology.
- The Department of Transportation provides oversight and funding for locally operated transportation systems—bus, subway, commuter rail, and para-transit services.

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 the 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.

Individuals and families note:

- satisfaction with existing community services;
- transportation remains problematic both in terms of access and cost, affecting participation in employment, education and recreation;
- increased accessibility and use of public recreation facilities is desired; and
- community attitudes will improve with increased participation of individuals with developmental disabilities in community recreation, arts, worship, sports, and social life.

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 for the Mentally Disabled, OMRDD, the Division of Human Rights and the State Office of the Advocate for Persons with Disabilities. Each of these agencies has a designated role in assuring the rights of individuals with disabilities at the systems level and quality of available services and support.

The DDPC has taken the lead on consumer empowerment initiatives with significant efforts in self-advocacy, citizen advocacy, Partners in Policymaking Training, Independent Parent Advocacy Networks, and self-determination. Under DDPC support, regional self-advocacy associations and the Self-Advocacy Association of New York State were established. Varied self-advocacy initiatives continue to thrive with a focus on self-determination for all consumers. Self-advocates are involved in finding solutions to transportation, legal, medical, and employment advocacy problems and improving community attitudes. As this movement has grown and prospered, self-advocates have become partners in developmental disabilities policy making.

Individuals note:

- barriers to self-advocacy and self-determination remain for many consumers;
- many employers, providers and families do not accept the goals or comprehend the concept of self-advocacy;
- need for increased competence of professionals in identifying and serving people with developmental disabilities;
- personal life enhancement projects in the community are needed to improve the quality of life for adults with developmental disabilities;
- adults with developmental disabilities must improve their financial literacy, so they will require less assistance with routine financial management activities; and
- a continued need for self-advocacy initiatives and activities that enhance self-determination goals, particularly person-centered planning.

UNSERVED AND UNDERSERVED GROUPS

General Barriers

Individuals from these groups indicate that the quantity and skills of the workforce are a significant deterrent to receipt of services. Further, the bias of the service system tends to be toward serving individuals with mental retardation and worker skill in dealing with multiple, severe, concurrent, and unusual disabilities tends to be limited.

Barriers Relating to Specific Groups

(A) **Group:** Individuals with developmental disabilities from culturally diverse populations.

Barriers Specific to Group: New York State is home to individuals from 178 different countries and 138 languages are spoken. About 1/3 of the population is from minority groups and over 3 million individuals 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 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.

(B) **Group:** Children and adults with developmental disabilities requiring services from multiple service systems.

Barriers Specific to Group: This group includes individuals with any kind of dual diagnosis (i.e. developmental disabilities and mental illness, sensory impairment, substance abuse, serious health conditions, offender status, etc.), severe and multiple disabilities, autism, cognitive and emotional limitations. These consumers and their families report difficulty in obtaining adequate and appropriate services to meet their needs.

(C) **Group:** Children and adults with developmental disabilities and challenging behaviors.

Barriers Specific to Group: This group includes individuals who manifest behavior problems that set them apart from their peers and the general public. Families of these individuals report that these behaviors are a significant deterrent to accessing needed services and are often the reason for suspension of or delay in receipt of services.

~

(D) **Group:** Individuals with developmental disabilities, other than mental retardation, who are eligible for services but are being excluded.

Barriers Specific to Group: This group includes individuals with significant learning disabilities, cerebral palsy and/or other physical disabilities, seizure disorders and epilepsy, Traumatic Brain Injury (TBI), attention deficit disorder, or mild developmental disabilities but no cognitive deficit. These individuals noted that the bias of the service system is toward persons with mental retardation and that they are often refused services even though their disability significantly restricts their functional capacity. Where services are available, they tend to be restrictive and do not meet their needs.

~

(E) **Group:** Individuals with developmental disabilities who are otherwise eligible but are not receiving services because of geographic barriers.

Barriers Specific to Group: This group includes individuals from rural, urban, isolated, and congested areas of New York State. These individuals report transportation and distance are significant barriers to receipt of services and that they have difficulty finding workers willing to travel to their homes.

New York State Developmental Disabilities Planning Council

State Plan

2002 - 2006

Objectives by Area of Emphasis

August 2001

AREA OF EMPHASIS: HEALTH

People are healthy and benefit from the full range of needed health services.

Goal Statement	Objectives
Goal HE 1: Expand appropriate and quality health care and related services available to children and adults with developmental disabilities.	**Objective HE 1.1:** By 2006, the DDPC will undertake at least two (2) additional activities that result in recommendations regarding the implementation and monitoring of managed care of children.
	Objective HE 1.2: By 2006, 100 families and 50 health care providers will be educated about health care benefits for children with developmental disabilities.
	Objective HE 1.3: By 2006, 50 health care provides will be educated about interventions and modification for delivery of appropriate medical care to children and youth with developmental disabilities.
	Objective HE 1.4: By 2006, ten (10) pieces of information about changes in the incidence, nature and cause of specific type of disabilities and availability of necessary supports and services will be identified/developed and disseminated.
	Objective HE 1.5: By 2006, at least five (5) effective and replicable health promotion and wellness programs for people with developmental disabilities will be established.
	Objective HE 1.6: By 2006, DDPC will establish capacity for at least six (6) local initiatives that promote replicable local health care networks that promote understanding, collaboration, and use of developmental disabilities services within generic health care and include culturally diverse organizations and neighborhood health centers.

AREA OF EMPHASIS: EDUCATION & EARLY INTERVENTION

Students reach their educational and developmental potential.

Goal Statement	Objectives
Goal ED1: Increase programmatic responsiveness and inclusion of children with developmental disabilities in education, early intervention, and child care programs.	**Objective ED 1.1:** By 2006, DDPC will assist nine (9) school districts to develop informational campaigns about the benefits of inclusive education and useful strategies for ensuring successful outcomes for both students with and without disabilities who are in an inclusive classroom.
	Objective ED 1.2: By 2006, DDPC will have collaborated with four (4) institutions of higher learning to include more inclusion strategies for general education teachers
	Objective ED 1.3: By 2006, DDPC will have identified at least three (3) strategies to improve the inclusion of children at the preschool level, especially in NYC.
	Objective ED 1.4: By 2006, at least three (3) activities and strategies that promote the inclusion of children with developmental disabilities in school sponsored activities, including but not limited to social activities, will be developed.
	Objective ED 1.5: By 2006, DDPC will improve the capacity of at least 24 school districts to better serve children with developmental disabilities.
	Objective ED 1.6: By 2006, DDPC will develop local capacity in 10 regions of NYS to train parents about the individualized education plan (IEP) emphasizing strength-based approaches and advocacy strategies.
	Objective ED 1.7: By 2004, the number of community based supportive partnership among schools, families and community-based agencies will have increased by 16.

AREA OF EMPHASIS: CHILD-CARE

Children and families benefit from a range of inclusive, flexible child-care options.

Goal Statement	Objectives
Goal CH 1: Increase programmatic responsiveness and inclusion of children with developmental disabilities in education, early intervention, and child care programs.	**Objective CH 1.1:** DDPC will increase the number of integrated childcare and respite program in NYS by 10 by 2004, and an additional 35 by 2006.

AREA OF EMPHASIS: TRANSPORTATION

People have transportation services that meet their personal and professional need.

Goal Statement	Objectives
GoalTR1: Decrease transportation-related barriers to participation in employment and community life.	**Objective TR 1.1:** By 2006, 80 adults with developmental disabilities will report increased employment and/or participation in community recreation and social activities through use of business-driven and informal solutions to transportation difficulties.

AREA OF EMPHASIS: RECREATION

People benefit from recreational, leisure, and social activities consistent with their interests and abilities.

Goal Statement	Objectives
Goal RE 1: Improve the quality of life and community participation for children and adults with developments disabilities	**Objective RE 1.1:** By 2006, DDPC will have established four (4) clusters of personal life planning and enhancement project in the community that improve the quality of life for adults with developmental disabilities.
	Objective RE 1.2: DDPC will increase the number of integrated recreation and socialization program in NYS by 15 by 2003, and an additional 40 by 2006.
	Objective RE 1.3: By 2006, NYS will have at least six (6) inclusive community recreational activities (including accessible beach and recreation areas) with guidelines for replication.

AREA OF EMPHASIS: OTHER COMMUNITY SUPPORT

Individuals have access to other services available or offered in a community, including formal community supports that enhance their quality of life.

Goal Statement	Objectives
Goal CS 1: Improve the quality of life and community participation of children and adults with developmental disabilities.	**Objective CS 1.1:** By 2006, DDPC will implement at least one new strategy for facilitating social inclusion of individuals with developmental disabilities.
	Objective CS 1.2: By 2006, 12 community entities (including religious congregations) will be physically accessible and programmatically inclusive.
	Objective CS 1.3: By 2006, DDPC will establish a clearinghouse for collecting, cataloging, developing, and disseminating material for changing public attitudes toward people w/DD.
Goal CS 2: Increase community capacity to include and serve children and adults with developmental disabilities from under-served populations.	**Objective CS 2.1:** By 2006, DDPC will have demonstrated three (3) culturally appropriate models of community inclusion for people with developmental disabilities from at least 3 under-served special populations.
	Objective CS 2.2: By 2006, at least three (3) effective strategies for improving services that address behavioral issues within the home, school community will be developed and demonstrated.
	Objective CS 2.3: By 2004, at least two (2) barriers to appropriate services for children and adults with the dual diagnosis of mental illness and developmental disabilities will be identified along with potentially viable solutions.
	Objective CS 2.4: By 2006, 15 regional grassroots plans for increasing access to development disabilities services in rural areas will have been developed, implemented, & evaluated.

	Objective CS 2.5: By 2006, at lest ten (10) regional grassroots plans for increasing access to developmental disabilities services in diverse communities will have been developed, implemented, and evaluated in a way that links developmental disabilities expertise and knowledge to community resources.
Goal CS 3: Increase service system reliance on self-determination processes and person-centered planning.	**Objective CS 3.1:** By 2006, the knowledge and skills of at least 125 families will be increased as they more through the following transition points: • Early intervention to Pre-School • High School to Work or Higher Education • Special Education to General Education • Institutions to home schools
	Objective CS 3.2: By 2006, nine (9) different models for improving critical life transitions will have been demonstrated, refined, adopted, and replicated.
	Objective CS 3.3: By 2006, the DDPC will have undertaken at least ten (10) additional activities for increasing ease of access and availability of assistive technology and durable medical equipment services and devices for individuals with developmental disabilities and their families.
	Objective CS 3.4: By 2006, the DDPC will have undertaken at least 4 additional activities that increase access to appropriate personal assistance services for individuals with developmental disabilities and their families.
	Objective CS 3.5: By 2006, four (4) different service systems will have adopted person-centered planning.
	Objective CS 3.6: By 2006, the DDPC will have engaged in at least four (4) activities that move the developmental disabilities service system so that it is based on self-determination processes.
	Objective CS 3.7: By 2006, DDPC will have demonstrated at least five (5) models for increasing meaningful participation in choice and decision making by individuals with developmental disabilities and family members.

AREA OF EMPHASIS: QUALITY ASSURANCE

People live free of abuse, neglect, financial, and sexual exploitations, and violation of their human and legal rights.

Goal Statement	Objectives
Goal QA 1: Increase the number of children and adults with developmental disabilities who live in permanent families.	**Objective QA 1.1:** By 2003, an action plan base on activities undertaken by a Federal Grant for the Families Together Adoption Project will be developed; this action plan will be implemented by 2006.
	Objective QA 1.2: By 2004, the support needs of biological families of children w/DD who become involved in the foster care system or are the subject of a Child Protective Services complaint or a PINS petition will be identified and integrated into an action plan.
Goal QA 2: Increase the quality and quantity of individuals involved in the developmental disabilities workforce.	**Objective QA 2.1:** By 2006, 100 professionals annually in at least 4 disciplines will demonstrate increased competence in identifying and serving people with developmental disabilities from special populations.
	Objective QA 2.2: By 2006, DDPC will identify, develop, and demonstrate five (5) models for increasing the supply and retention of direct support workers in the home and community.
	Objective QA 2.3: By 2006, the number of individuals with developmental disabilities and family members of individuals with developmental disabilities in the developmental disabilities workforce will have increased by 100 each year.
Goal QA 3: Develop strong cohesive developmental disabilities advocacy networking in NYS.	**Objective QA 3.1:** By 2006, at least 40 additional persons annually will have been trained through the Partners in Policy Making Training Program.
	Objective QA 3.2: By 2006, a network of Partners in Policy Making "graduates" will have been firmly established that includes at least 500 trained "Partners" and includes ongoing communication and support.

	Objective QA 3.3: By 2006, DDPC will strengthen existing independent parent advocacy network and support the advocacy activities 11 additional parent groups.
	Objective QA 3.4: By 2006, the DDPC will have identified at least 12 effective models for training individuals with developmental disabilities to become members of community boards of director/planning bodies that resulted in 60 individuals becoming members of such community boards/bodies.

AREA OF EMPHASIS: CROSS CUTTING

Impacting on all Areas of Emphasis.

Goal Statement	Objectives
Goal CC 1: Assure that the service need and quality of life for children and adults with developmental disabilities and their families are considered in policy and practice.	**Objective 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.
	Objective CC 1.2: Initiate at least one capacity-building or information dissemination activity annually that responds to an area of consumer and provider concern.

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 35 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 (D.D. 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 D.D. 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's grant funding initiatives through their communication and involvement with local community organizations and businesses seeking to develop and implement such worthwhile programs.

DISABILITY ?

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

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

DDPC INITIATIVES

The DDPC fulfills its responsibilities under the D.D. 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 D.D. 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:_____

_____

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 that 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 D.D. Act); and who are not managing employees of any other entity that receives funds or provides services under (the D.D. 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

Michael J. Mackin, Chairperson **Sheila M. Carey, Executive Director** **Duncan Whiteside, Vice-Chair**

Comments Section

NYS Developmental Disabilities Planning Council

State Plan 2002-2006

What do you think of our plan…

_____
_____
_____
_____
_____
_____
_____
_____
_____

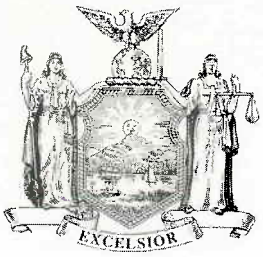
Suggestions to assist in achieving the goals and objectives in our plan…

_____
_____
_____
_____
_____
_____
_____
_____
_____

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

Dr. Anna Lobosco, Deputy Executive Director
NYS DDPC
155 Washington Avenue / Second Floor
Albany, NY 12210

Email: 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

PRSRT STD
US Postage Paid
Albany, NY
Permit No. 48