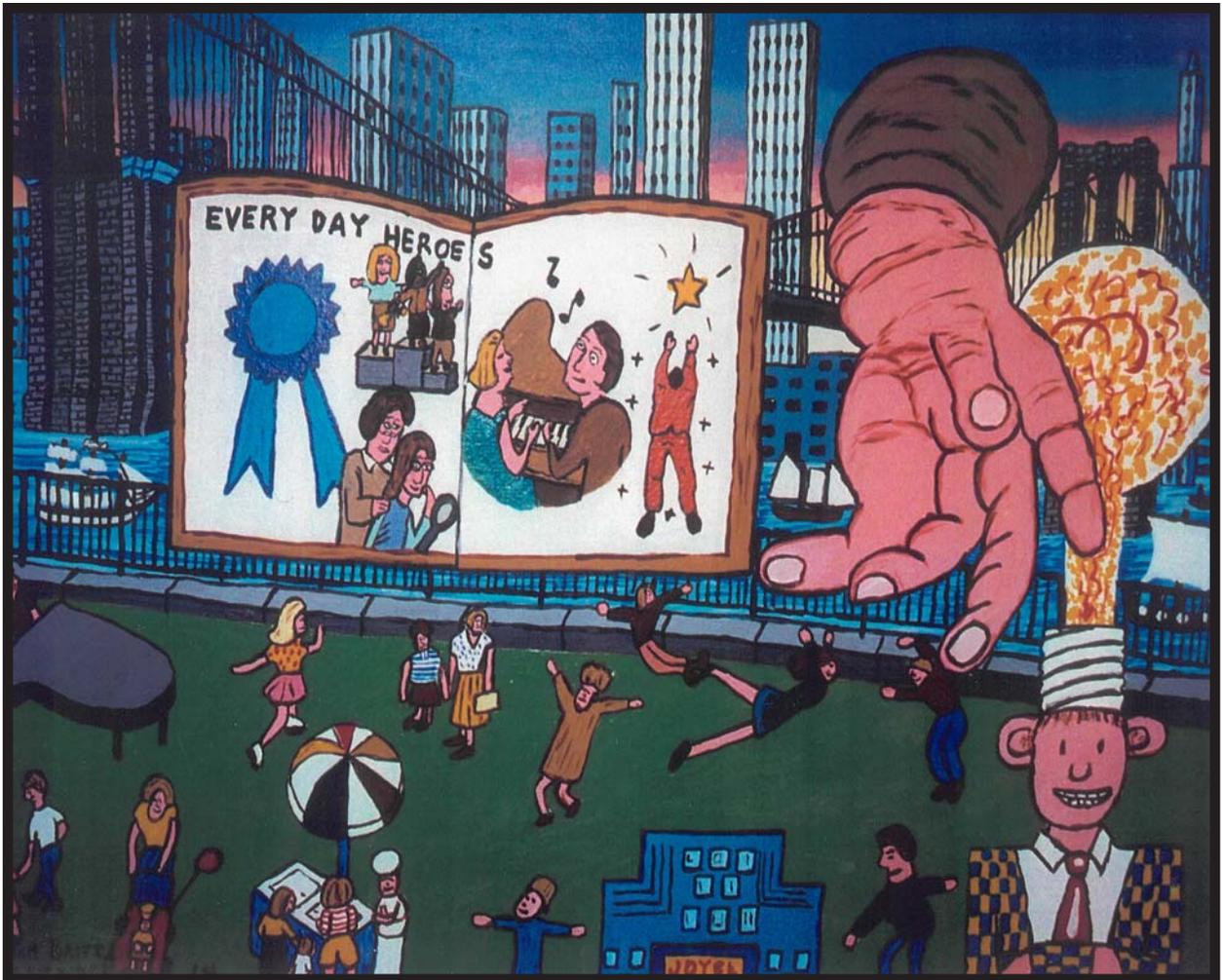


# The Five Year Comprehensive Plan

For the Period 2006-2010



New York State Office of Mental Retardation & Developmental Disabilities

**OMRDD**  
George E. Pataki  
Governor  
Thomas A. Maul  
Commissioner

March 2006

"Everyday Heroes"  
by William Britt  
2004 - Oil

**About the cover art**

William Britt was inspired to create the cover art painting in honor of the many direct support professionals who reached out to him throughout his life.

The hand represents the kindness of helpers who touched his life along the way and is a symbol of human concern.

The light bulb represents the good ideas that direct support professionals bring into the lives of others and the insight gained from sharing the journey.

The human figures engaged in the activities of everyday life symbolize membership in the lives of people with disabilities. Through the soaring figure, William reminds us that people can rise above their limitations and fly on the supportive wings of others who care.



STATE OF NEW YORK  
**OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES**

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March, 2006

Dear Friends and Colleagues:

I am pleased to present you with the final copy of the *Five Year Comprehensive Plan for the Period 2006-2010 for the New York State Office of Mental Retardation and Developmental Disabilities*.

As you may recall, OMRDD held Constituent Forums prior to the development of the draft Plan published in January, 2005. The final Plan incorporates the feedback from public hearings held in February and March of 2005. Highlights from the hearing testimony are summarized in an Appendix and in modifications to the text of the Plan.

One of the most exciting opportunities on our collective horizon is the expansion of New York State's Options for People Through Services (NYS OPTS). This initiative, along with our State's long-term commitment to NYS-CARES II, strongly underscores Governor Pataki's continuing dedication to the needs and aspirations of citizens of New York State with developmental disabilities and their families.

OMRDD's Five Year Comprehensive Plan is the culmination of our partnership efforts with parents, self-advocates, family members, nonprofit agencies, provider associations, local governments and state staff. I am confident the Plan meets the collective interests of all stakeholders in developing a responsive, effective, and efficient service system of the highest quality for people with developmental disabilities-one that supports people in living lives full of individual dignity and choice, as well as meaningful relationships and contributions.

I wish to express my appreciation to the many contributors who reviewed the Plan and who offered testimony about services and supports provided, funded, and regulated by OMRDD. I look forward to our continued collaboration and success on behalf of the people we serve.

Sincerely,

A handwritten signature in black ink, appearing to read "T. Maul", written over a light-colored background.

Thomas A. Maul  
Commissioner



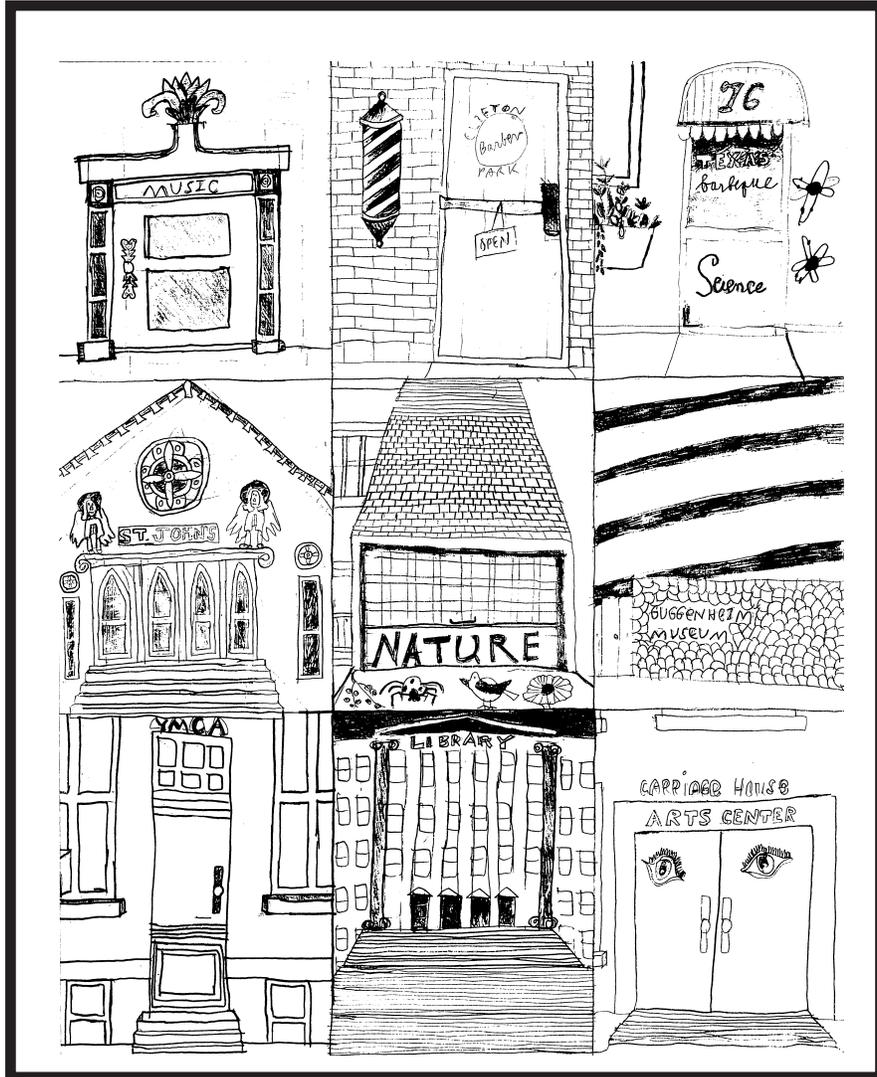
**This Plan is dedicated to the memory of**

**John W. Jacobson, Ph.D.**

**who contributed to every  
Comprehensive Five Year Plan  
produced by OMRDD  
since it became an agency in 1978,  
including this Plan.**



# Table of Contents



"Doors in the Community"

by James Kenneally

2004 - Lead Art Pencil

Sponsored by:

Living Resources Carriage House Arts Center



# OMRDD

## The Five Year Comprehensive Plan

For the Years 2006 - 2010

### TABLE OF CONTENTS

---



<b>Executive Summary</b>	i
<b>I. Introduction: Continuity and Change</b>	<b>1</b>
<b>Mission</b>	4
<b>Governing Principles</b>	4
<b>A Preview of Tomorrow's Services</b>	5
<b>Developmental Disabilities</b>	6
<b>Overview of Current Supports and Services</b>	7
<b>Development of the Service System</b>	9
● Evolution of the HCBS Waiver	14
● Unmet Needs	16
● Future Challenges	16
<b>II. Planning with the People We Serve</b>	<b>19</b>
<b>Groups Consulted in the Planning Process</b>	20
<b>2003 OMRDD Constituent Forum Themes</b>	23
<b>The Role of Local Government</b>	27
<b>III. Priorities for Tomorrow</b>	<b>29</b>
<b>NYS-CARES II and NYS OPTS</b>	30
● NYS OPTS Steering Committee	31
● Guiding Principles for NYS OPTS	31
● The Potential of NYS OPTS for Systems Change	32
<b>Delivering Supports and Services That Customers Want</b>	33
● Self-Determination and Self-Advocacy	33
● Quality Staffing	34
● Collaboration among Governmental Agencies	38
● Special Populations	39
● Person Centered Planning and Participation in Planning	42
● Transportation	43
● Access to Information	44
● Community Inclusion and Community Building	45
● Work and Employment	46
● Family Support Services	47

## TABLE OF CONTENTS (Continued)

<b>III. Priorities for Tomorrow (continued)</b>	
<b>Other Improvements in Service Quality</b>	<b>47</b>
● Quality Assurance and Quality Improvement	47
● Appropriate Service Settings	49
● Managing the HCBS Waiver	49
● Improving the Process of Housing Development	50
● Improving Health Care Practices	51
<b>IV. Vision and Goals</b>	<b>55</b>
<b>Major Initiatives for the 2006-2010 Plan Period</b>	<b>56</b>
<b>Comprehensive Five-Year Plan Goals</b>	<b>57</b>
<b>Appendix A: Public Hearing Summary</b>	<b>63</b>
<b>List of Tables and Figures</b>	
Table 1. 2003 Prevalence Estimates Developmental Disabilities	7
Figure 1. OMRDD Serves Individuals with a Wide Range of Ages	9
Figure 2. OMRDD Serves a Wide Variety of Multicultural Groups	10
Figure 3. The Number of Individuals Living in Institutions Has Decreased Dramatically Since 1975	11
Figure 4. As the Number of Individuals Living in Institutions Has Decreased Community Opportunities Have Increased	11
Figure 5A. The Typical Size of Residential Programs Has Decreased	12
Figure 5B. The Percent of Smaller Community Residential Programs Has Increased	12
Figure 6. Day Service Totals Have Dramatically Increased Since 1990	13
Figure 7. Family Support Services Dollars Have Increased Since 1990	14
Figure 8. HCBS Waiver Enrollees Increased Dramatically Since 1990	15
Figure 9. Medicaid Service Coordination Has Increased Substantially	15
Table 2. Needs Identification (DDP-4): Number of Individuals with Developmental Disabilities Reporting a Need for Service	16

# Executive Summary



"Bus"

by Charlotte Walwyn

Circa 2000 - Acrylic

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# Executive Summary

## Background and Overview

Two elements have characterized the operations of the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) over the 28 years since it became a separate agency in 1978: a commitment to high quality services and to the participation by the people involved in the system in its planning and operations. While the agency's concept of what constitutes quality services has changed over time from concern with physical health and safety in congregate settings to community membership and realizing the full potential of each person, the underlying mission and goal of providing individualized high quality services has been the constant around which all planning has been done.

OMRDD's agenda for the 2006-2010 comprehensive five-year planning period centers on the same two elements: our collective commitment to excellence in quality and oversight, and to the participation by every part of the service system in the planning, implementation and evaluation of our programs. In this new millennium, our system's focus is more sharply centered than ever on meeting the needs of each person and family we serve.

OMRDD will achieve its vision through initiatives designed with and for the people it serves. The goal is to maximize opportunities for people with developmental disabilities to participate in, and contribute to, communities throughout the State of New York. Two such important initiatives are the second phase of our nationally acclaimed and highly successful New York State-Creating Alternatives in Residential Environments and Services (NYS-CARES) program, called NYS-CARES II; and the New York State

Options for People through Services (NYS OPTS) program, through which individualized services and supports will be developed and enhanced by consumer- and family-directed approaches to service design and delivery.

OMRDD's current supports and services are primarily based on its Medicaid Home and Community Based Services (HCBS) Waiver, which has made it possible for OMRDD to fund an increased array of individualized services. Supports and services are increasingly more consumer driven and designed.

Since its beginnings as an independent agency, OMRDD has faced and surmounted a range of challenges that have arisen out of its transformation from an institutional to a community-based system of supports and services.

New York's institutions have by and large been replaced by certified community-living options that provide flexible residential supports and services to the more than 36,000 individuals who are served in them. Since 1990, the community residential system has continued to expand, with more than 50 percent growth, and day services opportunities have also increased dramatically. Further, the types of day services have changed, with services provided through employment and day habilitation becoming dominant.

Medicaid Service Coordination (MSC) provides a vital link to information and service options for individuals with mental retardation and developmental disabilities. It is the role of the service coordinator to work with people and families to develop a plan of care that assures that individuals who are eligible for services through OMRDD receive the assistance they need. As of 2004, more than 61,000 New Yorkers are benefiting from OMRDD's MSC program.

Providing supports and services to families that assist them in their efforts to care for their loved ones at home continues to be an important goal for OMRDD. The Family Support Services program was created two decades ago to address the many needs of families, and today there are varied options available through this important program. These services are designed, directed and monitored by family support consumer councils in every Developmental Disabilities Services Office (DDSO) across the state. Although the expectations of families and individuals with developmental disabilities have changed over 25 years, many of the challenges are the same--to pursue excellence in developmental disabilities services by responding to each person's strengths, needs, and preferences, and to fulfill the desire for a full and varied life characterized by community membership and contribution.

### **Planning with the People We Serve**

As important as is a written plan, so is the process that OMRDD uses to develop the plan. This process relies on formal and informal consultation with a wide variety of people who are involved in the OMRDD service system. Collaboration gives the planning process vitality and a focus on providing meaningful contributions that might otherwise be missed with more mechanical approaches. Widespread and frequent consultation with the full range of constituencies for developmental disabilities has proven to be a powerful and successful planning methodology. Groups consulted range from the statutory advisory panel, the Mental Retardation and Developmental Disabilities Advisory Council, to such groups as the Self-Advocacy Association of NYS. During 2003, OMRDD held eight Constituent Forums to solicit public input on available services and to initiate the development of this comprehensive plan.

### **Priorities for Tomorrow**

As OMRDD continues toward achieving its mission and goals, its highest priorities

remain the provision of quality services and the participation of all constituencies in the planning, implementation and evaluation of those services. Therefore, all programs and services that are developed include the elements of quality and participation as essential components. Among those initiatives that will propel OMRDD into the new millennium are the following:

#### **NYS-CARES II and NYS OPTS**

NYS-CARES II and NYS OPTS are initiatives that will have a broad impact on OMRDD's ability to meet its strategic goals.

From its inception through March 31, 2004, the NYS-CARES program provided 9,134 people with places to live in the community, and family support services for thousands more people living at home with their families waiting for a residential opportunity. NYS-CARES II represents a 10-year commitment by the State of New York to provide living arrangements and supports for people with developmental disabilities and their families. It will provide additional out-of-home residential opportunities, new opportunities for in-home services, increases in day services, and added funding for Family Support Services. An initial allocation of resources included in the plan has been completed and stakeholders will participate in a mid-course evaluation of the program. Having NYS-CARES II in place ensures that OMRDD can address the demand for out-of-home residential services in the future.

The major OMRDD program initiative during the plan period is NYS OPTS, a person- and family-driven systems change initiative using the Organized Health Care Delivery System model permitted under federal Medicaid regulations. NYS OPTS will profoundly influence the variety, quantity, and quality of services in the OMRDD system in the future by using contracts that provide highly individualized services to specific service recipients. People with developmental disabilities and

their families will shape the design and delivery of the services and supports offered through these contracts, as well as identify the outcomes by which success will be evaluated. The contractors will be voluntary providers of service. NYS OPTS is being pursued to increase choice and individualization of services for people with developmental disabilities. Providers will gain the flexibility to customize solutions that will better meet the expectations of their customers. NYS OPTS has great potential for positive systems change.

OMRDD organized a steering committee with representation from individuals with developmental disabilities, families, advocates, service providers, geographic areas, and program and service types to advise OMRDD on NYS OPTS. Steering committee involvement assures that the NYS OPTS process is inclusive, and that the ideas and preferences of stakeholders are given voice. The steering committee's Guiding Principles for NYS OPTS will direct the selection of pilot project proposals and constitute the standards for evaluating projects.

### **Delivering Supports and Services That Customers Want**

OMRDD has based its agenda for the next five years on the needs, hopes, and desires of its customers, as expressed at the Commissioner's Constituent Forums held during the summer of 2003. Participants were pleased with the general direction of OMRDD efforts and mostly suggested improvements to existing programs, services, and initiatives. Over the next five years, OMRDD, working with all its partners, will seek to improve the supports and services in each of the areas of concern identified at the Constituent Forums. These issue areas include:

- Self-determination and self-advocacy.
- Quality staffing.
- Collaboration among other entities involved in the total service network.

- Special populations (dual diagnosis, autism, and others).
- Person centered planning and participation in planning.
- Transportation.
- Access to information about available services.
- Community inclusion and community building.
- Work and employment.

The Conference of Local Mental Hygiene Directors is a statutorily designated partner in the planning process. Through the Partnership Planning Process and the annual submission of local government plans, the counties have pointed to services to children, adults, and people with dual or multiple diagnoses as areas of concern. These topics are consistent with concerns expressed at the forums and will be addressed during the plan period.

### **Improving the Way Services Are Administered and Delivered**

In addition to addressing concerns directly identified by individuals with developmental disabilities and other stakeholders as priorities, OMRDD must address other administrative and service delivery issues that are important to improving system performance. These are:

- Quality assurance and quality improvement.
- Reconfiguring institutional resources.
- Managing the HCBS Waiver.
- Improving the process of housing development.
- Improving health care and clinical practices.

### **Vision and Goals**

OMRDD's vision for the next five years will feature continuity in the provision of the highest quality services, while expanding the system's capacity to offer more individualized services to each person and family. This vision will be implemented through the pursuit of the major agency initiatives that are planned for the

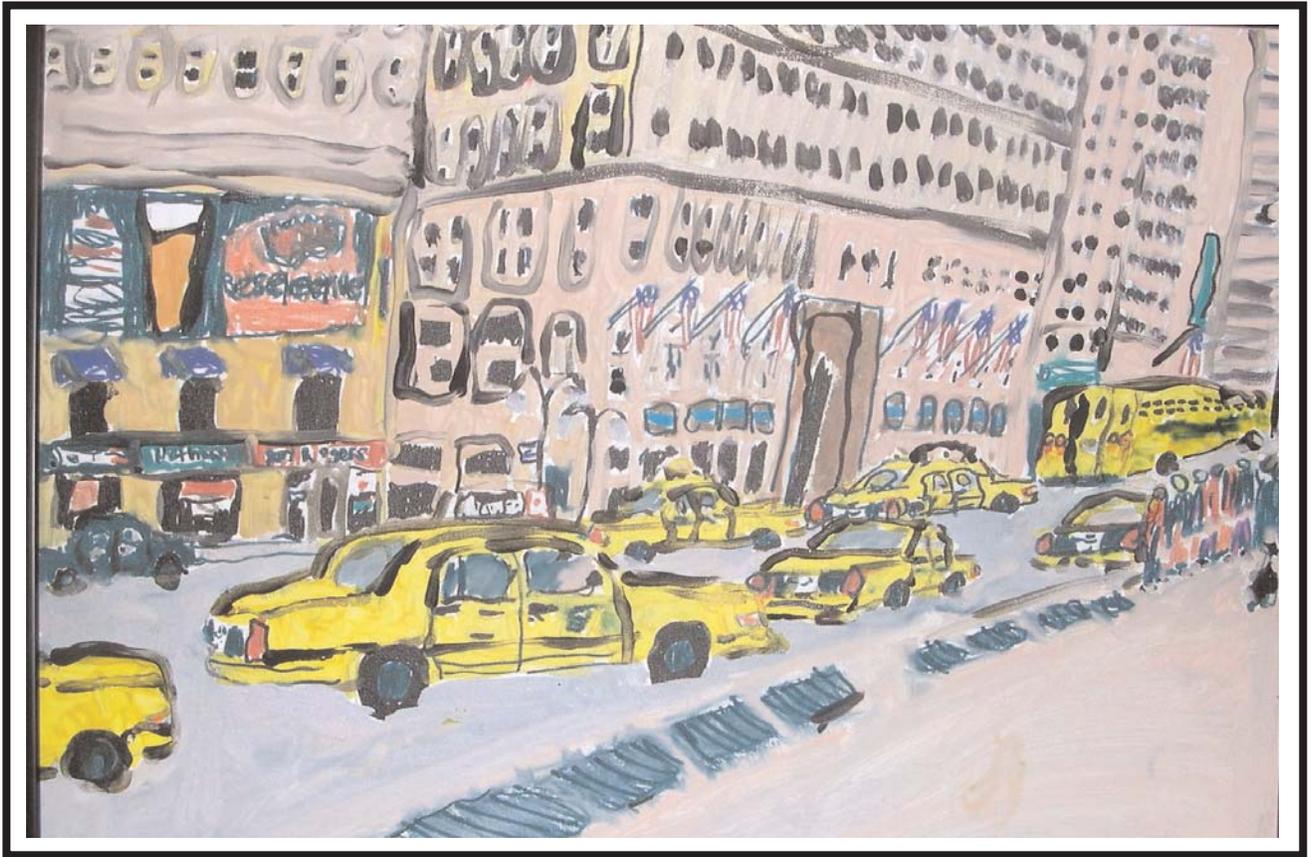
Comprehensive Five-Year Plan period of 2006-2010. These initiatives will help realize a service system for people with developmental disabilities and their families that emphasizes individualization, innovation, and choice, and that leads to quality outcomes. These initiatives are:

The Comprehensive Five-Year Plan concludes with a list of specific goals for each issue area. These goals will guide detailed actions over the plan period.

- **Participation and Collaboration.** OMRDD will continue to build on its tradition of seeking the participation of stakeholders, and especially parents and individuals with developmental disabilities, in planning for and providing services. In addition, OMRDD will further its work with the Self-Advocacy Association of New York State (SANYS) in realizing our mutual vision for full community participation.
- **NYS OPTS.** This program is designed to provide a wide array of affordable options that promote inclusion and personal choice.
- **NYS-CARES II.** This program is critical to continuing the success of the original NYS-CARES initiative in providing out-of-home residential services to those from the community who needed them.
- **Individualized Supports and Services.** OMRDD will continue to make supports and services more customer designed, directed, and individualized.
- **Workforce.** OMRDD will continue to work for higher wages, a stronger career structure and other elements of a quality work life for the direct support professional work force. In addition, the Commissioner will establish a Direct Support Professional Advisory Committee.



# Introduction: Continuity and Change



"Taxis at Penn Station, NYC"

by Susan Brown

2005 - Acrylic

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# I. Introduction: Continuity and Change

In 2003 the Office of Mental Retardation and Developmental Disabilities (OMRDD) celebrated the 25th anniversary of its founding as a separate state agency. Since OMRDD's inception, there has been continuity in the way the agency has pursued its mission, including a commitment to high quality services and attention to the choices of the people it serves. These elements have helped OMRDD establish a record of delivering on commitments to improve the quality and variety of services and supports it offers to New Yorkers with developmental disabilities and their families. While pursuing quality services and involving the people it serves in the design and implementation of programs have been integral to the service system, the definition of quality services and the methods of achieving participation have changed over time.

In its beginning years, quality centered on physical safety and health, mainly in congregate program settings. Listening to people with developmental disabilities and their families helped change how quality is viewed. The words "belonging and becoming" now characterize the way OMRDD aims to support people with developmental disabilities. "Belonging" recognizes the universal desire to experience membership within a community, to be included, and to fully and freely participate in relationships, activities and opportunities. People who work for OMRDD and in the field of developmental disabilities now appreciate the importance of belonging, expressed as being included in the planning, design and delivery of supports and services. "Becoming" captures the essence of all people as unfulfilled potential. All people have the

capacity to grow, learn, and develop, to become more capable, independent and self-directing than they are today. At the core of service provision is the goal of assisting people in realizing their full potential; thus the drive for more individualized supports and services.

Likewise, the methodology for obtaining input and information from people involved in the service system to shape operations has evolved over the years. The implementation of the New York State-Creating Alternatives in Residential Environments and Services (NYS-CARES) program provides an outstanding example. NYS-CARES, the historic five-year program ending March 31, 2004, provided out-of-home residential services for people living in the community who were waiting for such services. It had the goal of providing 8,100 people with the opportunity to live in a community residential setting. It exceeded this goal by creating out-of-home residential opportunities for 9,134 people. In addition, it provided thousands of people with family support and other at-home services while they waited for residential opportunities consistent with their personal plans to become available. The nationally acclaimed initiative has been extended and expanded in NYS-CARES II, announced in 2003.

OMRDD's willingness to listen to its customers and to incorporate what it learned into agency goals and operations helped it succeed. These and other successes will serve as building blocks in undertaking the major projects of the next five years. These building blocks include:

- **Participation:** Section II of the Plan describes in detail the many and varied constituency groups that OMRDD regularly consults with to ensure that its policies and practices derive from an inclusive dialogue. These include advisory councils, parent and self-advocacy associations, multicultural groups, oversight bodies, and local governments.

Broad participation in service development is a powerful planning method that has allowed the system of services to evolve in a way that best serves customers.

- **Outreach:** It has been demonstrated that grassroots activities are the most effective methods of outreach. These approaches connect on a personal level to promote understanding and awareness of developmental disabilities and the services that are available. Each Developmental Disabilities Services Office (DDSO) will develop a locally based outreach plan for implementation over the next five years.
  - **Customer Satisfaction:** Intensive surveys of people involved in the NYS-CARES program provided OMRDD with solid information regarding its successes as well as targets for improvement within its service system. Noteworthy was the finding that over 90 percent of individuals and families who received residential opportunities through NYS-CARES gave high ratings to their service coordinators. OMRDD will continue to measure its success through ongoing customer satisfaction surveys, designed and implemented in collaboration with families, advocates, and nonprofit providers.
  - **Technology-Assisted Individualization and Choice:** OMRDD is utilizing geomapping technology to facilitate the process of choosing a residential opportunity. This technology will assist individuals receiving services, family members, and their service coordinators to make more informed decisions about residential options for New Yorkers with developmental disabilities. OMRDD's work in the area of geomapping received a **Best of New York** designation from the Center for Digital Government.
- OMRDD will continue to develop and expand this system.
- **Waiting Lists:** Understanding need is essential for developing appropriate service opportunities. Therefore, OMRDD continually verifies its waiting list information through direct outreach and input from citizens throughout the state. OMRDD will continue to ensure that accurate waiting list information is obtained and maintained statewide.
  - **Funding Mechanisms:** OMRDD utilizes flexible funding mechanisms to facilitate individualized services and consumer choice. In order to preserve and expand the service system for individuals with developmental disabilities, OMRDD will continue to research and develop flexible funding methods to achieve its goals.
  - **Confidence in the System:** OMRDD has helped to increase confidence in the system through its success with NYS-CARES and other important initiatives in recent years. Achievements on behalf of the people OMRDD serves have instilled hope for parents, family members and the people receiving services. OMRDD will build on those successes to further enhance confidence in the system over the next five years.
- OMRDD enters the 2006-2010 comprehensive five-year planning period with an ambitious agenda centering on the implementation of NYS-CARES II and the establishment of a major new program, New York State Options for People Through Services (NYS OPTS). OMRDD is confident of success in these and the other items on its agenda for the next five years because of its record of creating services and supports of high quality. It is a history of commitments made and commitments kept. OMRDD's practice of working in a participatory and

collaborative manner with the many participants in its service system plays an important role in establishing a service system that enjoys broad support.

This Plan consists of four chapters. Chapter 1 opens with the agency's mission and governing principles statements that have proved their value in directing and motivating the agency. It then describes the centerpiece initiatives for the Plan period of 2006-2010. After defining OMRDD's target population, it describes current services and their historical development in narrative and graphic formats. Chapter 2 describes OMRDD's planning process. It lists the groups that participate in the planning effort. Chapter 2 also provides insight into the responses and preferences provided by constituents at a series of forums conducted around the state. Chapter 3 takes those customer-defined priorities, matches them against what OMRDD is doing now and identifies a key challenge in that area. It also describes other major OMRDD activities and their challenges. Chapter 4 puts major activities in the context of a vision for the future. It ends with a list of specific goals for each priority area.

## Mission

The mission of the OMRDD is:

- To develop a comprehensive, integrated system of services which has as its primary purposes the promotion and attainment of independence, inclusion, individuality, and productivity for people with mental retardation and developmental disabilities;
- To serve the full range of needs of people with mental retardation and developmental disabilities by enhancing community-based services and developing new methods of service delivery;
- To improve the equity, effectiveness, and efficiency of services for people with mental retardation and develop-

mental disabilities by serving people living in the community as well as those in developmental centers, and by establishing accountability for carrying out the policies of the state with regard to such people; and

- To develop programs to further the prevention and early detection of mental retardation and developmental disabilities.

OMRDD's Developmental Disabilities Services Offices (DDSOs) are responsible for providing services, supports, and programs in one or more counties. These offices seek to provide specially designed person centered assistance to each individual with developmental disabilities. In partnership with individuals with developmental disabilities, families, staff, non-profit providers, and local governments, these offices seek to improve the quality of life of individuals and their families.

## Governing Principles

OMRDD has adopted a set of governing principles to define and strengthen quality supports and services. The five governing principles are:

- A person with a developmental disability shall relate to his or her family, friends, and communities when and how he or she chooses, consistent with the rights and wishes of others.
- A person with a developmental disability shall be as independent as possible and determine the direction of his or her life.
- A person with a developmental disability shall have the opportunity to make life choices that do not compromise health and safety, and such choices shall be respected and valued.
- A person with a developmental disability shall have the opportunity to communicate his or her feelings,

including fears, and have them addressed, and not be subjected to fear of harm or reprisal in connection with the provision of supports and services.

- A person with a developmental disability shall receive supports and services that are effective and meet his or her needs.

## A Preview of Tomorrow's Services

As a result of the close working relationship among families, advocates, the non-profit provider community and OMRDD, and based upon the success of the original NYS-CARES initiative, Governor Pataki introduced NYS-CARES II in 2004. Through this 10-year plan, OMRDD will develop additional services to meet individual needs. Through a multiyear allocation process, NYS-CARES II will provide an additional 1,900 new out-of-home residential opportunities, 600 new opportunities for in-home services and 370 new opportunities for day services.

NYS OPTS is a new program based on a provision of the federal Medicaid law and regulations called an "Organized Health Care Delivery System" (OHCDS). OMRDD is establishing itself as an OHCDS and will contract with developmental disabilities service providers to deliver services to eligible individuals. This program is designed to provide people receiving services, the public and nonprofit providers with a wide array of affordable options that promote inclusion and personal choice and offer flexibility and opportunity for efficient and effective use of the resources available. All participants in the system will benefit from increased flexibility and will receive individualized services. It is the goal that any efficiencies achieved through NYS OPTS will further support NYS-CARES II and serve more people in other ways.

This program is unique in that its implementation and direction were defined

through a collaborative effort of individuals who are receiving services, their parents and other family members, self-advocates, nonprofit providers and provider associations, local government, state staff and other interested representatives. In effect, those who will use it designed this program.

The participation of individuals and families will not end with the design of NYS OPTS. They will participate in putting together the specifications for individual NYS OPTS pilot project proposals and evaluating those projects that are implemented. This involvement should encourage projects that promote individual choice and quality of life outcomes. The personal satisfaction of the individuals involved in each NYS OPTS project will be an important factor in evaluating that project's success.

OMRDD began implementing this program in 2004 utilizing a statewide pilot program. Based on the experiences of these initial pilots, OMRDD will seek to expand successful projects to other parts of the state. Participation is strictly voluntary with consumer satisfaction as a key element in determining its success.

The potential impact of NYS OPTS might be compared with aspects of the HCBS Waiver. During the past decade, OMRDD concentrated on fully using the Home and Community Based Services (HCBS) Waiver as a vehicle for financing and developing an array of supports and services. This was a major administrative change that had and continues to have a profound effect on the quantity and quality of supports and services. It enables the delivery of supports and services that are more individualized than in the pre-Waiver days. NYS OPTS is another big change in administrative systems with the potential to enable OMRDD and its providers to deliver even more individualization in supports and services, consistent with the national direction for individuals with disabilities.

## Developmental Disabilities

To understand the service system for people with mental retardation and developmental disabilities in New York State, it is helpful to know the definition of developmental disability and to have a sense of the prevalence of the covered conditions in the general population. Section 1.03(22) of the NYS Mental Hygiene Law defines developmental disability and is the basis for determining eligibility for OMRDD-funded services. Developmental disability is defined as a disability of a person which:

- (a) (1) Is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, familial dysautonomia, or autism;
- (2) Is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons;
- (3) Is attributable to dyslexia resulting from a disability described in subparagraph (1) or (2) of this paragraph;
- (b) Originates before such person attains age twenty-two;
- (c) Has continued or can be expected to continue indefinitely; and
- (d) Constitutes a substantial handicap to such person's ability to function normally in society.

At least one of the three conditions described in paragraph (a) must occur in combination with the latter three requirements for a person to be eligible for OMRDD-funded services. A functional assessment of the impact of the disability upon the person's ability to function normally in society, such as an assessment of adaptive behavior and independence skills, is necessary to determine eligibility regard-

less of the diagnosis of the disability. Mental retardation is the sole exception, as a clinical diagnosis of mental retardation would satisfy all of the criteria automatically, based on how mental retardation is defined in the Mental Hygiene Law.

To increase the quality and consistency of eligibility assessments and awareness of the eligibility process and standards, OMRDD issued guidelines to aid eligibility determination. These guidelines, entitled *OMRDD Advisory Guidelines--Determining Eligibility for Services: Substantial Handicap and Developmental Disability*, are posted at the OMRDD website ([www.omr.state.ny.us](http://www.omr.state.ny.us)) under "general information and publications," making them available to individuals with developmental disabilities, families, providers and clinicians alike.

The table on the following page shows estimates of the prevalence of developmental disabilities in the population, based on a model derived from the professional literature and used in OMRDD's past plans. The estimates are based on the general population projections from the 2003 adjusted federal census developed by New York State. The only substantive difference from past estimates is for autism. Newer research expands this category to include Autism Spectrum Disorders and, accordingly, it has been found that it occurs far more frequently than was projected in earlier prevalence studies. Many biological and environmental factors have been suggested for this increase. However, considerations such as changing clinical criteria for autism, better case finding, better early detection, improved access for young children to diagnostic services, and better training of diagnosticians also account for some part of the higher estimate of autism and Autism Spectrum Disorders.

It is important to stress that although this table shows, for example, that 271,625 people are projected to be diagnosed with mental retardation, many of these same

**Table 1. 2003 Prevalence estimates (conditions) for categorical developmental disabilities as defined in the New York State Mental Hygiene Law**

Disability Conditions	Number of Affected People	Population Percentage Affected	Rate
All Instances of Autism	52,991	0.279%	3.40/1,000
All Instances of Cerebral Palsy	25,487	0.134%	1.34/1,000
All Instances of Epilepsy	21,696	0.114%	1.14/1,000
All Instances of Mental Retardation	271,625	1.45%	14.5/1,000
All Instances of Neurological Impairment	35,556	0.187%	1.87/1,000
Total People Affected	341,755	1.80%	18.0/1,000

Figures are based on an estimated 2003 NYS census of 18,976,457. All counts of conditions and people are based on developmental disabilities-qualifying severity of disability. Because some people have more than one of the listed conditions, the total for people is less than the total for instances of conditions. Changes in autism estimates are based on findings from the Center for Disease Control's Metropolitan Atlanta Study. Small increases in eligible people with familial dysautonomia are included under Neurological Impairment. Source: Bureau of Planning and Service Design.

people may be diagnosed with cerebral palsy or epilepsy. Because of cases of multiple disabilities, the total number of instances of these conditions is higher than the total number of people affected.

There is a large difference between the number of people who are projected to have developmental disabilities and the number who receive services. There are several reasons for this:

- Many people receive services from systems other than the developmental disabilities services system.
- Some people lack access to information about developmental supports and services.
- Some people are known to their primary health care providers but have not been, or choose not to be, referred to developmental services agencies and resources.
- Some people are registered through needs assessment efforts, but do not yet participate in services.

## Overview of Current Supports and Services

The HCBS Medicaid Waiver, in combination with pre-existing financing mechanisms, has made it possible for OMRDD to fund an increased array of individual-

ized types of services. Services funded through the waiver and in other ways are organized within the framework of the Individualized Services Environment (ISE) and include: Residential and Day Habilitation, Supported Employment (SEMP), Respite, Environmental Modifications, Adaptive Devices, Consolidated Supports and Services (CSS), Fiscal/Employer Agent Services, Pre-vocational Services, Family Education and Training (FET), Plan of Care Support Services (PCSS), and Transitional Supports. Supports and services are consumer-driven and designed.

The waiver allows people who would qualify for admission into an Intermediate Care Facility for the Developmentally Disabled (ICF/DD, sometimes referred to as an ICF/MR) to live with their families, in their own homes, a Family Care home or an Individualized Residential Alternative (IRA) and to receive services supported by Medicaid. While the waiver has meant a substantial move towards more normalizing situations for those living in certified residences, it is the waiver's ability to provide services to people living with their families or in their own homes that has had the most revolutionary impact on the number of people with developmental disabilities that can be served.

**Service Coordination** assists persons with mental retardation and developmental disabilities and their families in gaining access to services and supports appropriate to their needs. OMRDD delivers almost all service coordination through its Medicaid Service Coordination (MSC) program. MSC is provided by qualified service coordinators and uses a person centered planning process in developing, implementing and maintaining an Individualized Service Plan (ISP).

**Housing Supports** through OMRDD encompass both certified and non-certified options. Certified housing alternatives include semi-independent living, family living situations, housing with 24 hour available on-site assistance and training, and housing with both 24 hour, on-site assistance and training and specific intensive medical and behavioral supports.

Available non-certified housing options and supports include home ownership financed through low-income home ownership programs, independent living with individual supports, home sharing, services from generic housing organizations, family owned homes, and the use of trust funds to meet long-term housing needs.

**Adult Day Supports** involve a range of opportunities such as supported work, job coaching, adult social or community activities, senior day programs, habilitative or vocational skills training in sheltered employment programs, day training services, day habilitation options (both center-based and "without walls"), and intensive therapeutic and habilitation services through day treatment services. Supported work options include supported individual jobs, enclaves or workstations in industry, mobile work crews and entrepreneurial models.

**Family Supports** are goods, services and subsidies granted to:

- (a) Provide a quality of life comparable to similarly situated families without a family member having a disability;

- (b) Maintain family unity;
- (c) Prevent premature or inappropriate out of home placement;
- (d) Reunite families;
- (e) Enhance parenting skills;
- (f) Maximize the potential of the family member with a disability; and
- (g) Promote community integration and inclusion.

Services that are provided as family supports include day, evening, after school, day-weekend, or overnight respite, day or evening recreation, counseling, service coordination, parent or caregiver training, advocacy, benefits and entitlements assistance, transportation, behavior management, peer support, homemaker services, environmental modification, and family reimbursement.

**Individual Supports** are provided to assist adults with developmental disabilities in establishing their own households or independent living by renting or owning their own homes. Eligible individuals include those ready to leave a certified community or institutional placement, ready to move out of their family's home or needing supports to live on their own.

**Self Determination and Consolidated Supports and Services** are provided in close collaboration with the Self-Advocacy Association of New York State. A self-determination project using CSS funded through the HCBS Waiver, is underway. People with developmental disabilities are empowered to make key decisions about how they will live their lives. Participants themselves and their "circles of support" (committed friends, family members and advocates chosen by the person) develop individualized service plans and budgets and control the resources used to implement the plans. They choose the services and supports that they need, who will provide them, and how they are provided.

**Clinic Services** primarily provide long-term therapies to people with developmental disabilities. Clinics serving persons

with developmental disabilities and their families are either Article 16 clinics (certified by OMRDD) or Article 28 clinics (certified by the State Department of Health).

**Technology Related Assistance for Individuals with Disabilities (TRAID)** is provided through regional centers to help people with disabilities obtain technological assistance in the communities where they live. For example, TRAID offices will assist a person with disabilities find and obtain an appropriate assistive device, such as computer software. TRAID services are administered by the Commission on Quality of Care and Advocacy for Persons with Disabilities.

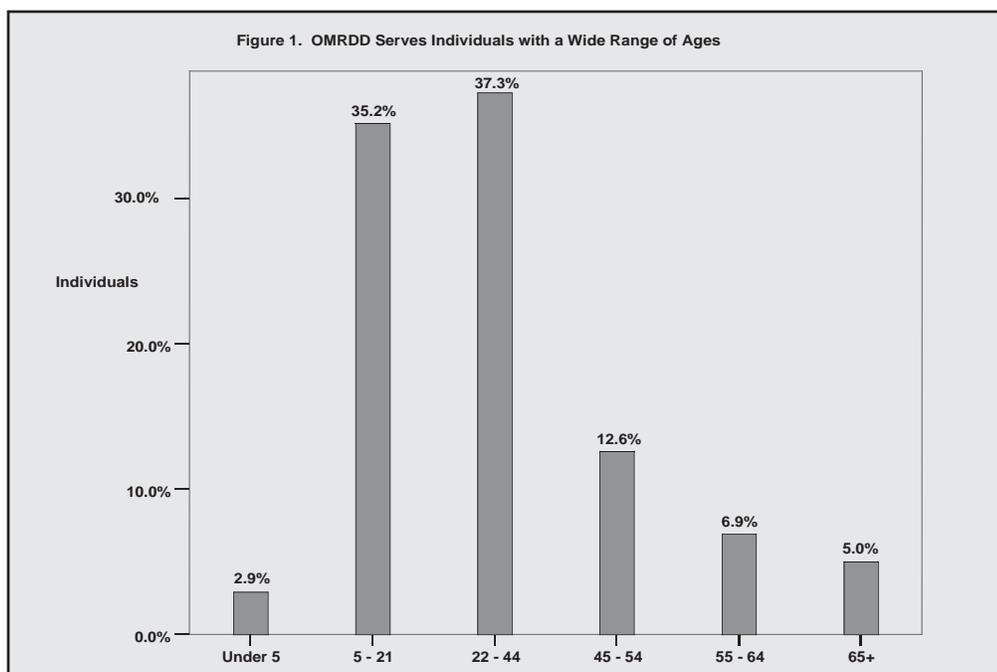
## Development of the Service System

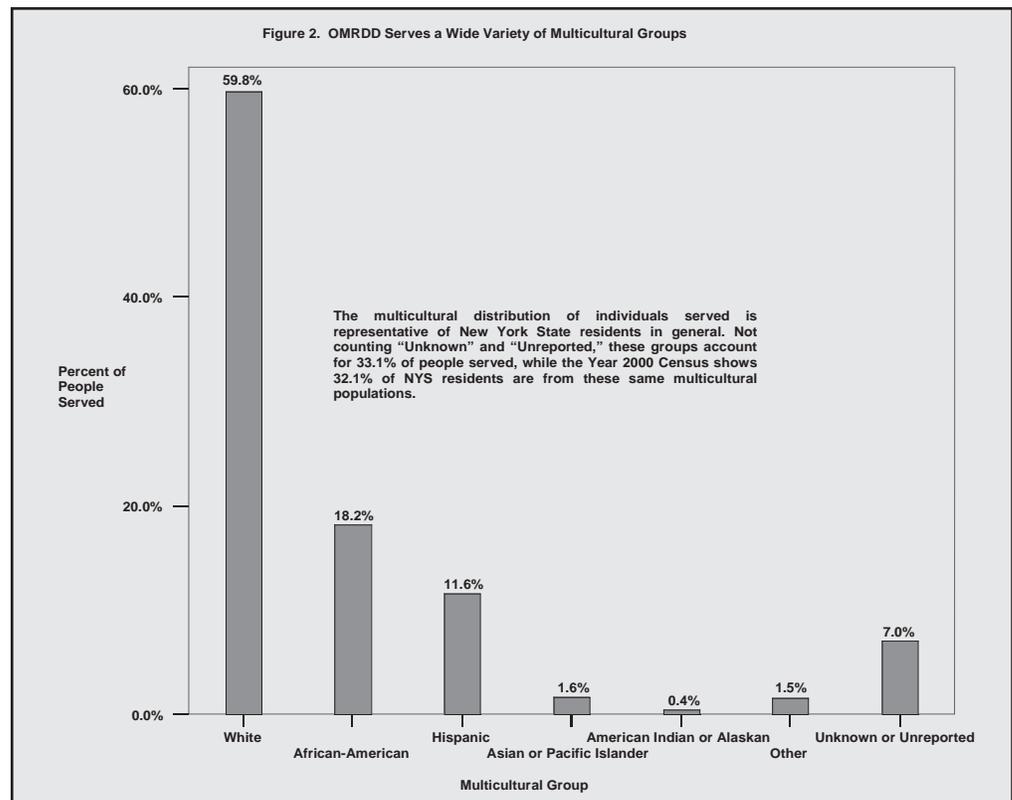
Since its beginning as a separate agency, OMRDD has faced and surmounted a range of challenges that arose from the transformation of an institutionally-oriented system organized around developmental centers to a network of community-based supports and services throughout the state that are responsive to the diverse needs and aspirations of people

with developmental disabilities and their families.

The figures that follow describe in numbers where the service system is today and how it got there. They depict who is served by age and ethnicity, and chart the continuous downsizing of the developmental center census as well as the increasing focus on community-based services in New York over the past 30 years. Figures show that the size of the typical living arrangement has been continually reduced and that the number of people receiving day supports and service coordination has been increasing each year. Consistent with this philosophy, funding for family support services has shown a steady rise over the past several decades. Today, New York's service system for people with developmental disabilities represents the most comprehensive and well-funded system of its kind in the United States.

The age range of individuals OMRDD serves underscores the necessity to develop age-appropriate services and supports. Figure 1 illustrates the following important characteristics of the population OMRDD serves:



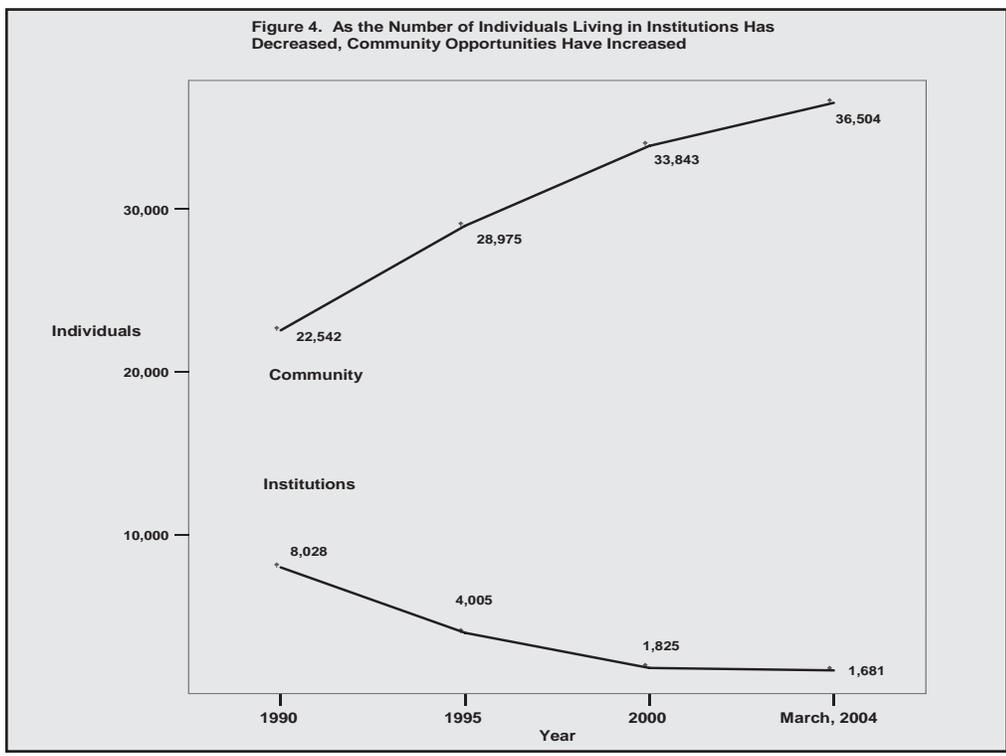
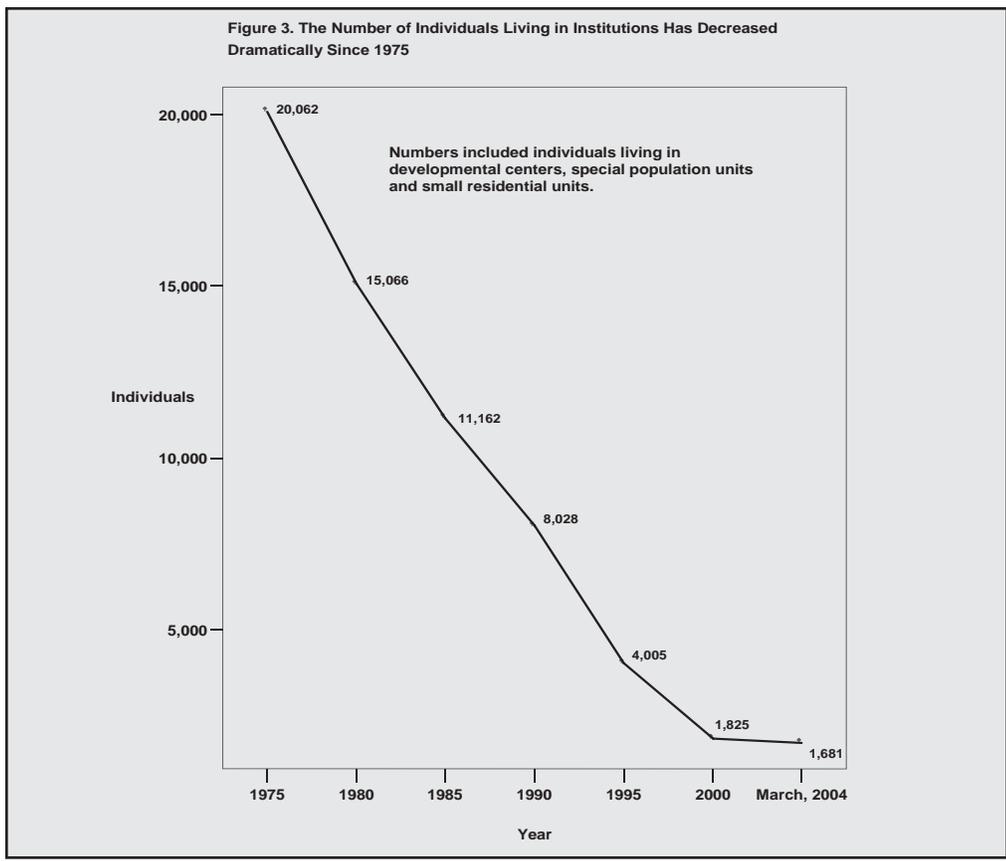


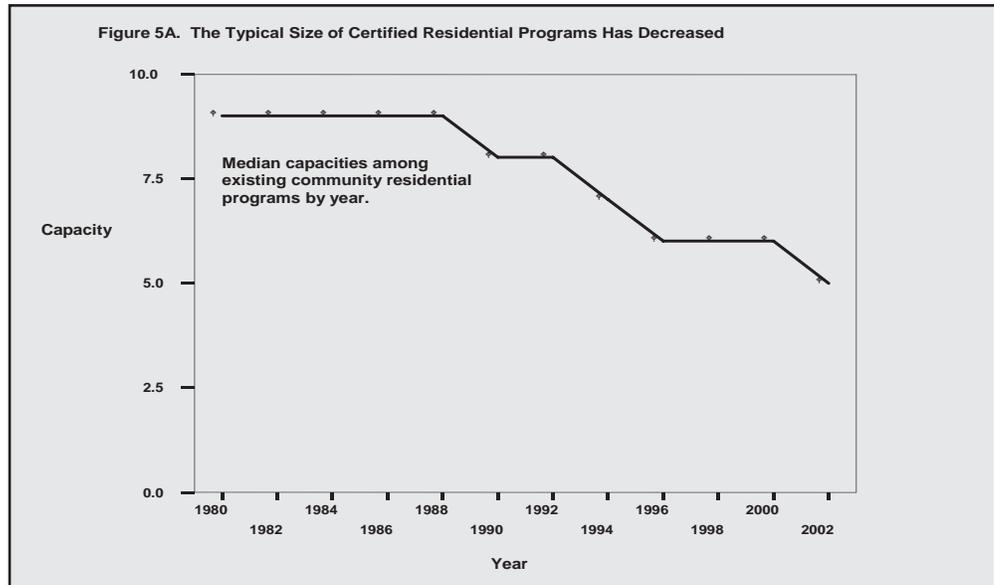
- More than one third are young adults, ages 22- 44.
- A significant number of school-aged children and their families receive services. Most of these children are served in their own homes and most OMRDD services are ancillary to services provided by their families and local educational and social services agencies.
- Nearly a quarter are over 45 years of age.

The fact that one-third of individuals served are from federally defined multicultural groups indicates that OMRDD must make the development of culturally appropriate services and supports for many different groups a high priority. The urban centers of New York State, and especially New York City, have scores of cultural and ethnic communities that are afforded equitable access to the developmental disabilities service system. Since census trends towards multiculturalism are projected to continue, adequately serving these groups will be an increasing challenge in the years ahead.

Over the past two decades, perhaps the greatest challenge and highest system priority was to design and build a network of community-based services. At OMRDD's inception more people were served in developmental centers and other congregate care settings than in community locations. Today community services have grown into a comprehensive resource for people with developmental disabilities and their families in localities throughout the state. More New Yorkers have moved from developmental centers to individualized community-based living situations than in any other state in the nation and New York's reliance on institutional settings is greatly diminished.

At its zenith, the institutional capacity in New York State was approximately 22,000 beds. It is important to note that today the institutional resource has been replaced with a much larger network of certified flexible community living options that serve over 36,000 people. In-home supports provided in non-certified residential settings add significantly to that number.

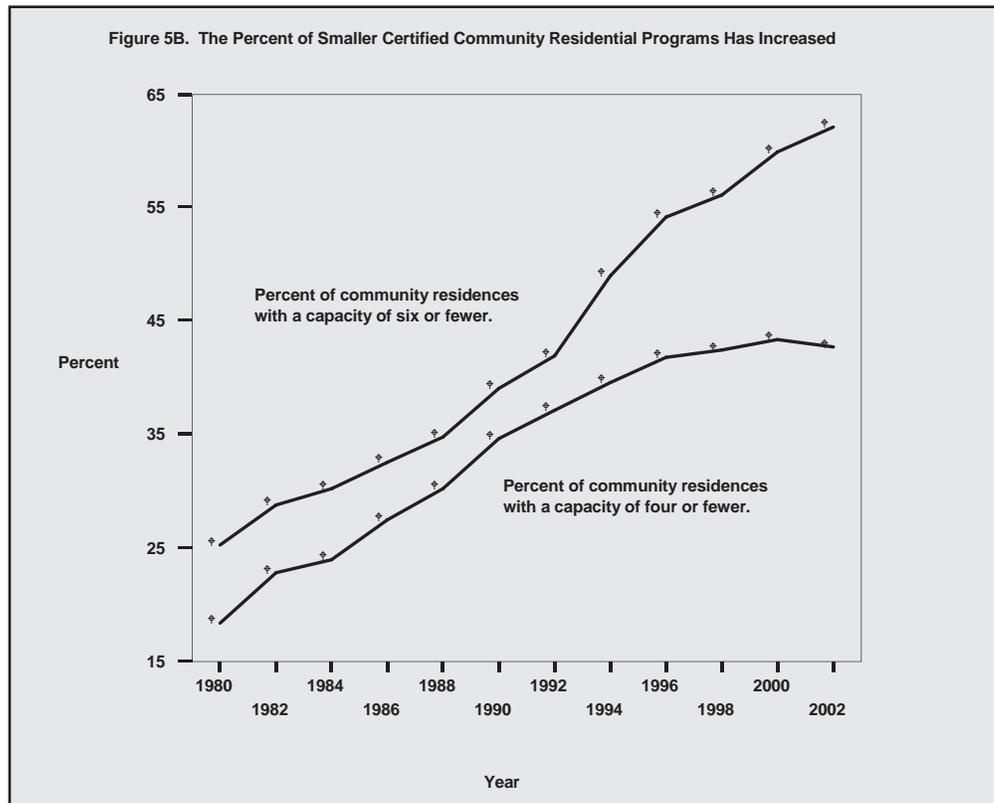


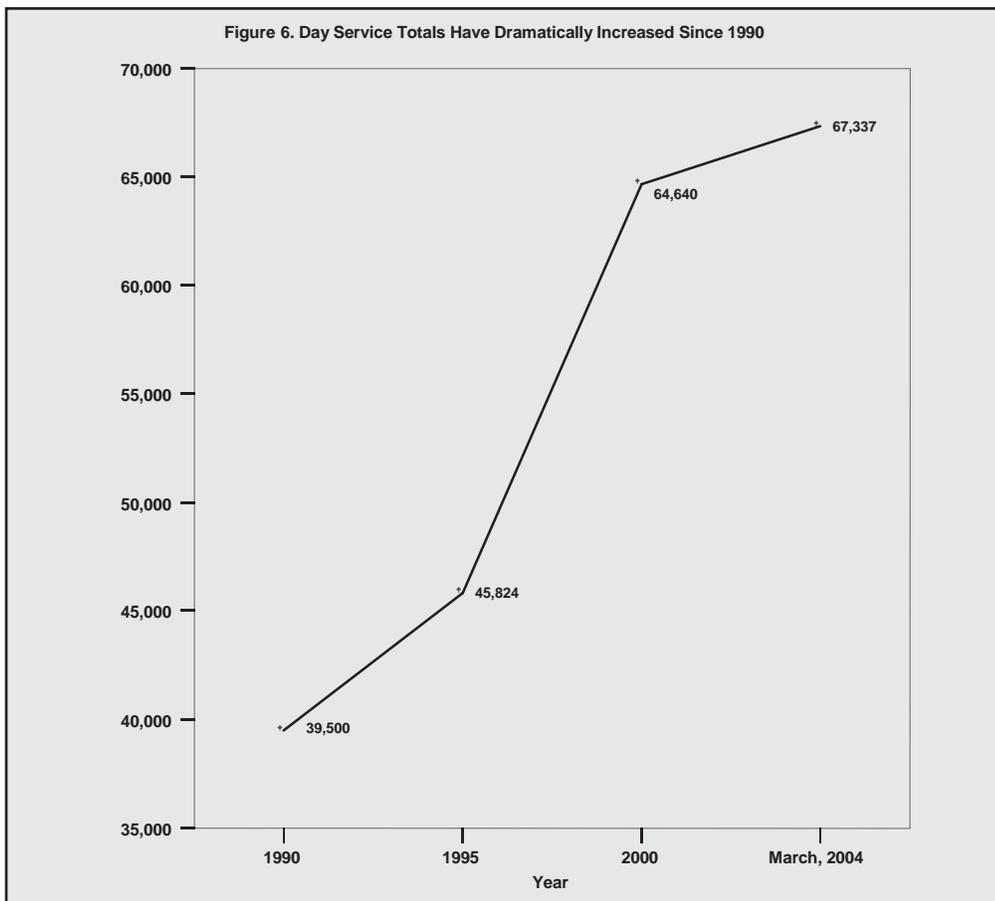


It is important to note that the community residential system continues to expand, with more than 50 percent growth since 1990. Nearly 2,500 certified opportunities have been added in the last four years. The IRA, smaller and more home-like, has replaced the ICF/DD as the most typical

certified living arrangement. Figures 5A and 5B reflect that homes are getting smaller and represent a larger share of the community-based residential system.

Figure 6 shows the large overall growth in day services from 1990. The changing





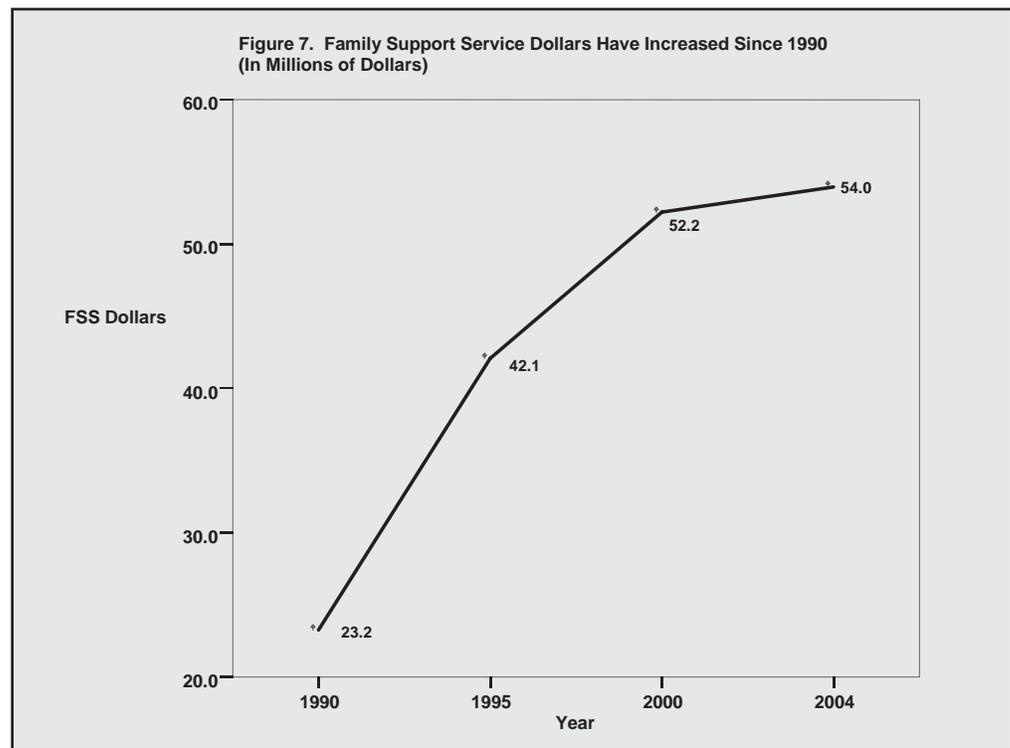
composition of the types of services within day services is also important. Day Treatment peaked at 20,235 in 1995 and dropped to 12,689 in 2004. Sheltered Work peaked in 1990 at 17,991 and stood at 12,267 in March of 2004. Similarly, there has been a decline in Day Training, from a high of 3,444 in 2000 to 1,255 in 2004. While these forms of day services have declined in numbers, the decline has been more than made up for by the development of Day Habilitation, which did not exist in 1995, yet rose to 13,198 by 2000 and to 28,416 by 2004. Integrated Employment stood at 10,420 in 2000. In 2002 and 2003 this program was renamed "Supported Employment" and recast from a contract to a fee-for-service basis. There were 8,268 enrollees in Supported Employment as of March 2004. There is a significant drop in enrollment from the former Integrated Employment program to the new Supported Employment program. The main reason for the drop in enrollment is the transfer of people in the program who did not meet OMRDD eli-

gibility criteria to the New York State Education Department's (SED) Office of Vocational and Educational Services for Individuals with Disabilities (VESID), which more appropriately meets their needs. No one lost services as a result of this transfer.

Some important points regarding day services are:

- Day services opportunities continue to grow.
- Day Habilitation, which came into existence with the HCBS Waiver in the 1990s, is now the predominant day service modality.
- Day Habilitation and the recast Supported Employment provide significantly more latitude for the development of individualized supports and services than the programs they eclipsed.
- Participation in Sheltered Workshops continues gradually to decline.

Prior to the implementation of the Family



Support Services program, families had to seek and obtain out-of-home living situations for their loved ones in order to get any services. In order to preserve the family unit, enabling families to stay together for as long as possible, and to address the needs of families and their members with developmental disabilities, OMRDD established a broad array of family support services that are now available throughout the state.

The growth in support to families caring for members with developmental disabilities at home is one of the more important changes in the transformation of the developmental services system from an institutionally-based system to a community-based system. Figure 7 understates this change because many services, such as respite and in-home habilitation, that were originally paid for with Family Support Services appropriations are funded today through HCBS Waiver. The transition in funding mechanisms for these services has enabled OMRDD to focus on providing additional supports for families.

### Evolution of the HCBS Waiver

By the late 1980s OMRDD realized that

the way many of its services were funded through Medicaid was hindering meeting the demands for system growth as well as diversification and individualization of services and supports. As a result, OMRDD developed its HCBS Waiver that promised more flexibility for a wider variety of programs and services. This is now the largest such waiver program for people with developmental disabilities in the country. The HCBS Waiver has allowed OMRDD to:

- Serve many more people in need;
- Expand the range of services available; and
- Create services that are both more appropriate and individualized and less expensive than conventional Medicaid services.

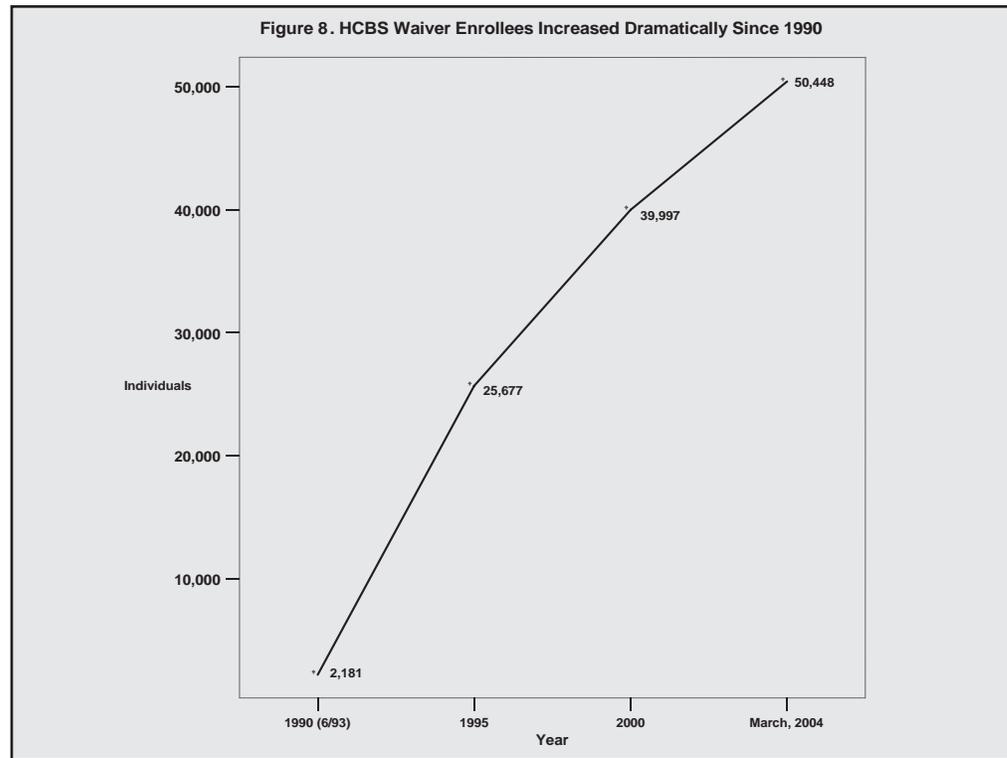
In addition, it is within the HCBS Waiver that many of the ideas on individualizing services have been put into practice.

Through the Waiver, OMRDD has been able to:

- Encourage the implementation of person centered planning processes throughout the state;
- Recognize the active roles of self-

advocates and self-advocacy organizations;

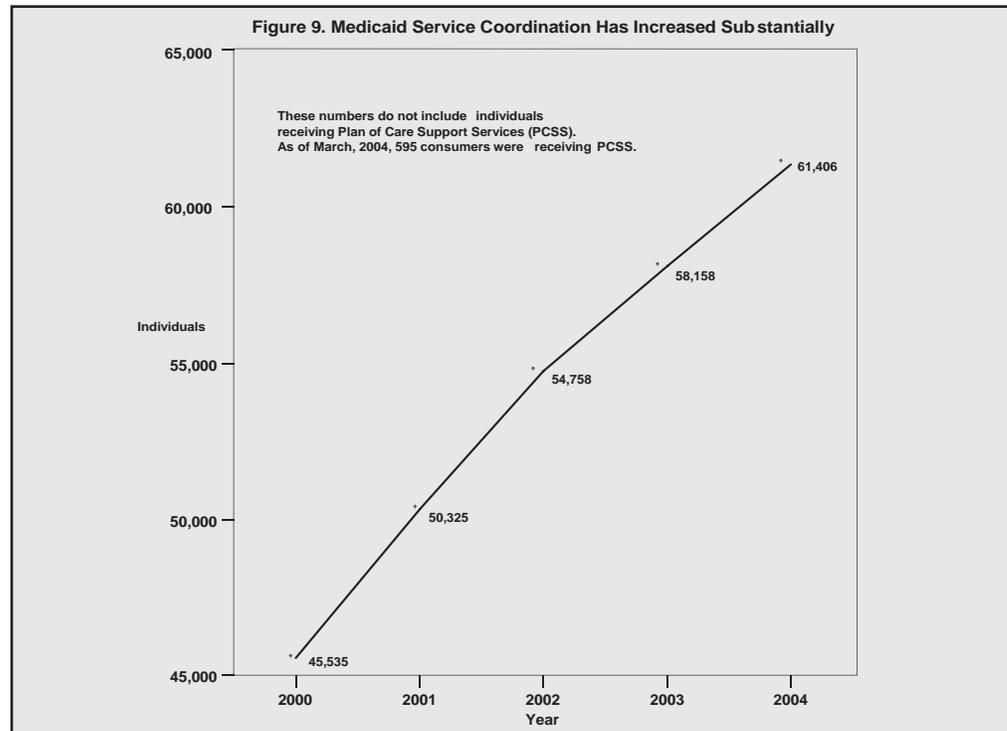
- Develop "day programs without walls" models;
- Introduce self-determination options, and encourage self-direction;
- Redefine quality services and supports and acceptable outcomes for people receiving services; and
- Promote a more contemporary view of people with disabilities as contributing citizens in their communities.



In the original Medicaid programs for people with developmental disabilities, such as the ICF/DD, everybody in the program received the same slate of services. The HCBS Waiver created an environment in which services are separated or "unbundled." This approach has advantages for individuals, in that they don't have to receive services they don't need, and for programs, in that the designs can be tailored to the individuals in them. For the individual, however, operating in an unbundled service environment with many more choices creates the need to have someone assist in putting together a coherent plan of services from the menu of formal OMRDD services and natural supports available in the community. This is the function of the service coordinator. Historically, OMRDD evolved two programs of service coordination: HCBS Waiver Case Management and Comprehensive Medicaid

**A note on Figures 8 and 9:**

Comparing Figures 8 and 9 shows that enrollment in MSC is considerably larger than it is for the HCBS Waiver. This is because more liberal Medicaid eligibility criteria apply to MSC, whereas an additional, more restrictive criteria applies to eligibility for the HCBS Waiver.



Case Management. In 2000 these two services were eliminated and replaced with a newly designed single service, Medicaid Service Coordination (MSC). As Figure 9 demonstrates, MSC has grown rapidly since its launch.

### Unmet Needs

As expectations for services rose in the wake of entitlements for educational services and other public benefits and programs, OMRDD found that, like developmental disabilities services agencies in other states, it was confronted with a growing list of people seeking residential services. In response, Governor Pataki established NYS-CARES in August 1998, a five-year initiative that identified pressing needs, provided services to assist families in their homes, and targeted residential development to individuals and their families in need. NYS-CARES was extremely successful, placing 9,134 people into residential settings. In follow up surveys, nearly 90 percent of sampled individuals and families expressed high levels of satisfaction with both their new homes and staff. In addition NYS-CARES provided thousands of people with family support and other at-home services while

they waited for housing opportunities to become available in line with their personal plans. While NYS-CARES addressed the immediate demand, people have continued to ask for new or alternate services and supports. OMRDD collects this information on a form called the Developmental Disabilities Profile-4 (DDP-4). Needs information as of March 31, 2004 is found below in Table 2.

NYS-CARES II is in place to deal with the need for out-of-home residential services. One of the lessons OMRDD learned in the administration of the original NYS-CARES program was the importance of accurate and current needs data. OMRDD sharpened its collection methods on needs data during NYS-CARES and is committed to further improving data collection methods and the accuracy and timeliness of needs information in the Plan period of 2006-2010.

### Future Challenges

Since the need for basic services has diminished for many and the focus has shifted to assuring that the services provided are appropriate to an individual's needs and are of their own choosing, the

**Table 2. Needs Identification (DDP-4): Number of Individuals with Developmental Disabilities Reporting a Need for Service**

District Office	No. of Individuals with MRDD NYS-CARES Residential Waitlist	No. of Individuals with MRDD Reporting a Daily Activity Need	No. of Individuals with MRDD Reporting an Individual and /or Family Support Services Need
Broome	167	521	1,058
Capital District	412	888	2,540
Central New York	358	801	2,672
Finger Lakes	793	1,752	3,513
Hudson Valley	573	1,266	2,203
Long Island	826	1,590	2,176
Sunmount	132	305	954
Taonic	173	616	788
Western New York	491	791	2,732
<b>Upstate Total</b>	<b>3,925</b>	<b>8,530</b>	<b>18,636</b>
B. Fineson	356	1,559	2,658
Brooklyn	623	1,964	3,007
Metro New York	580	1,708	3,518
Staten Island	141	304	507
<b>NYC Total</b>	<b>1,700</b>	<b>5,535</b>	<b>9,690</b>
<b>Statewide Total</b>	<b>5,625</b>	<b>14,065</b>	<b>28,326</b>

Notes:

1. It is important to note that 91% of people on the NYS-CARES residential waitlist, 78% with a daily activity need, and 84% with an individual or family support need are already receiving some type of OMRDD service.
2. Individuals with developmental disabilities may be included in more than one category of need.
3. NYS-CARES Waiting List as of 03/31/04.
4. "Daily Activity Need" includes the following services: Supported Employment (5,642), Day Habilitation (5,008), Pre-Vocational (1,886), senior activities (1,210) and Day Treatment (708).

challenges before OMRDD today are in some ways novel. This is coupled with the sense that the overall expectations of families and individuals with developmental disabilities have changed over 25 years. At the same time many of the challenges are the same-to pursue excellence in developmental disabilities services, and to respond to the desires of people with developmental disabilities to lead full and varied lives in their communities. OMRDD has worked closely with self-advocates, advocates, families and providers to better identify and define today's challenges. These partners are developing strategies that will further eliminate barriers to individualization and promote more tailored and collaborative community supports and services for people with special needs.



# Planning with the People We Serve



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## II. Planning with the People We Serve

Priority areas and associated goals developed collaboratively and over time will help guide the Office of Mental Retardation and Developmental Disabilities' (OMRDD) course during each annual budget cycle. OMRDD's budget request and supporting documentation constitute the annual update process and priority identification. The Plan for 2006-2010 also documents the significant achievements of our service system over past years in several goal areas.

As important as the goals and the written plan are, the process that OMRDD uses to develop the plan is equally important. This process relies heavily on consultation in both formal and informal situations with a wide variety of OMRDD stakeholders. Individuals with developmental disabilities and providers are accustomed to being heard and having their opinions taken into account. This collaboration itself is an OMRDD priority. It gives the planning process vitality and a focus on substance that is often missing from more mechanical approaches. OMRDD has a strong and broad-based coalition of advisory groups from which its policies and priorities emerge. Widespread and frequent consultation with the full range of constituencies for developmental disabilities has proven to be a powerful and successful planning methodology.

### Groups Consulted in the Planning Process

**Mental Retardation and Developmental Disabilities Advisory Council (MRDDAC).** OMRDD has a statutory advisory panel, the MRDDAC, which

participates in the process for developing goals and objectives as part of a comprehensive multiyear planning process, pursuant to Section 5.07 of the Mental Hygiene Law (MHL).

The Advisory Council members, with whom the Commissioner meets quarterly, include individuals with developmental disabilities, parents, nonprofit providers, advocates, government officials, and interested citizens who often have relevant backgrounds in education, health care, community service, parenting and self-advocacy. The Commissioner appoints members of the Advisory Council to a variety of OMRDD internal committees and workgroups. During each comprehensive planning cycle, the Council identifies liaison members who serve as reviewers and editors of various drafts. The full Council reviews and approves the comprehensive plan, including its mission, vision, policy directions and goals.

The Advisory Council plays a key role in the formal development of the comprehensive plan. Further, the agency's approach to strategic planning supplements the statutorily mandated consultation with contributions from customers and stakeholders at the grassroots level. There are established and maintained linkages to a wide variety of constituencies. These groups include the Advisory Council, but extend beyond it to more fully represent all major stakeholder groups: individuals with developmental disabilities and self-advocates, family members, nonprofit provider organizations, disability-specific advocates (e.g., autism, epilepsy), the Willowbrook monitors and the counties. Regular meetings are conducted with these groups and discussions at these meetings are used as a basis for setting both annual goals and objectives and broader policy and budget formulations.

The Advisory Council provides a forum to further debate and refine the ideas generated during meetings with these other

bodies. With its diverse membership, the Council's discussions generate a range of competing points of view for consideration as OMRDD seeks to reach consensus on a goal, objective, policy or program. The Advisory Council is an important source of endorsement for comprehensive initiatives like NYS-CARES, NYS-CARES II, NYS OPTS, enhancements to the HCBS Waiver or the self-determination pilot project, all of which keep New York State in the national forefront of innovation in supporting people with developmental disabilities and their families.

In OMRDD's broad-based outreach and consultative method of administration, the Commissioner frequently meets with the following groups. In addition he meets with other groups of self-advocates, advocates, parents and providers in the course of planned activities and special events over the course of each year:

**Statewide Family Support Services (FSS) Committee.** The Statewide FSS Committee is an official committee of the Advisory Council. This group is composed of parents and relatives of people with developmental disabilities and the Commissioner meets with it quarterly. The members of this committee represent local family support consumer councils that have been established at each DDSO. For many years they have provided valuable guidance to the family support program. Local family support councils annually conduct the Request for Proposal (RFP) process for new family support services development, and evaluate existing contracts on an ongoing basis.

**Provider Council.** This council represents the nonprofit providers of developmental disabilities services. Its 44 members include the executive directors of a representative sample of providers and the executive directors of the nonprofit provider associations of our state: New York State ARC (NYSARC), New York State Association of Community and Residential Agencies (NYS Rehabilitation

Association–NYSRA), Cerebral Palsy Associations of New York State (CP of NYS), InterAgency Council of Mental Retardation and Developmental Disabilities Agencies, Inc. (IAC), Alliance of Long Island Agencies for People with Developmental Disabilities, the Learning Disabilities Association of New York State (LDA of NYS), and New York State Catholic Conference. Nonprofit providers communicate with the Commissioner regarding their programmatic, regulatory and funding concerns, and suggest new directions that OMRDD should consider.

**NYS-CARES Oversight Committee.**

The Commissioner established a statewide oversight committee for NYS-CARES to assist OMRDD in monitoring compliance with the stated philosophy, mission and vision for NYS-CARES, tracking outcomes and periodically helping OMRDD assess consumer satisfaction with new residential and day opportunities. This group is composed of representatives from local oversight committees in each region, which have a similar mandate.

**NYS OPTS Steering Committee.**

As described in more detail in Chapter 3, this new committee and its three subcommittees represent a cross-section of stakeholders. The committee will be intimately involved in the design and evaluation of the NYS OPTS initiative. The committee has established Guiding Principles and will work to ensure that these principles influence the operation of the program.

**OMRDD Statewide Multicultural Service Provider Network.**

The Multicultural Service Provider Network meets regularly with the Commissioner and other senior management staff. These meetings provide a forum for the mostly small, nonprofit providers serving predominantly multicultural populations to discuss issues of interest and develop recommendations for OMRDD action. Approximately one-third of the individuals receiving OMRDD services are members of various multicultural populations.

To provide culturally appropriate services, OMRDD has enabled multicultural non-profit providers to broaden the types of services they provide. Small providers and new nonprofit providers need support to ensure that they develop effective and efficient business practices. OMRDD provides fiscal training for these nonprofit providers and supports consultants who offer other training. The open communications fostered in the meetings with the Multicultural Service Provider Network provide the basis for enhanced cultural sensitivity and responsiveness to multicultural concerns.

**Self-Advocacy Association of NYS (SANYS).** The Commissioner meets frequently with the executive board and other representatives of this advocacy organization that speaks on behalf of the people with developmental disabilities whom OMRDD serves. The Commissioner encourages self-advocate representatives to be open and frank in their discussions about what OMRDD is doing well and not so well. These discussions are extraordinarily useful in focusing OMRDD's efforts on the outcomes that are most important to individuals with developmental disabilities, targeting weaknesses in systems and developing strategies to improve performance.

Discussion with self-advocates led to an unprecedented two-day retreat in June of 2002 of 50 people: 25 DDSO directors and central office leaders and 25 self-advocates. The open communications at the retreat on issues important to self-advocates laid the foundation for further action at the local level across the state. An example was a self-advocacy fair in Brooklyn that drew 250 people. Self-advocates have said that the communications between self-advocates who were present and the leaders of the developmental disabilities services system engendered by the retreat is unique to New York State. The success of this event led to a second retreat with additional participants in September of 2004 with the

theme of building partnerships for community inclusion. Additional participants included executive directors of voluntary agencies with progressive records of creating innovative solutions for people wanting individualized supports and services, and parents of people with developmental disabilities who are noted for their advocacy of a good life in the community for their children. The retreat produced a vision for a future of full inclusion in the community that will guide OMRDD actions.

**Parent-to-Parent of NYS.** Parent-to-Parent of NYS is a statewide nonprofit organization with a mission to support and connect families of individuals with special needs. A support parent network of over 1,200 parents is the backbone of the Parent Matching Program. "Support Parents" are parents of individuals with special needs who have made the offer to speak one-to-one with "new" parents and share their experiences. Support Parents are provided skills building training, which includes an overview of how the program works, an understanding of the stages and emotions a parent or caregiver may be experiencing, as well as listening skills. In addition to the Parent Matching program, staff field telephone calls from parents of children with special needs who are looking for resources, services and information regarding such topics as medical services, therapies, specific illnesses or disabilities, and special education. Parent-to-Parent has received Federal funding to establish a Family-to-Family Health Care Information and Education Center for New York to provide information and training to families of children with special health care needs. The organization, which is primarily funded by OMRDD, is governed by a board of directors with members from across the state.

**Conference of Local Mental Hygiene Directors (CLMHD).** Composed of the 62 county mental hygiene directors, the CLMHD has a Developmental Disabilities Subcommittee of 12 members

interested in planning for developmental disabilities services. Senior OMRDD staff meets regularly with the subcommittee to update the members on budgetary and legislative matters that impact the counties. In 1996 OMRDD and CLMHD created a Partnership Committee to strengthen and reinvigorate the joint planning process mandated by Article 41 of the Mental Hygiene Law. That committee recommended steps for an improved process for joint planning among the county Community Services Boards, DDSOs and the public that OMRDD and the Developmental Disabilities Subcommittee of the CLMHD have since implemented. The Partnership Committee was reactivated in 2004 and continues in its mission of improving collaboration between state and local governments in planning.

**Developmental Disabilities Planning Council (DDPC).** As a member of the Executive Committee of the Developmental Disabilities Planning Council, the Commissioner meets regularly with the DDPC leadership, board and staff to discuss federal directions and priorities and to initiate joint activities. The DDPC distributes federal grants for work on disabilities topics. DDPC grants for pilot projects have supported OMRDD's efforts to advance understanding of service quality and to initiate innovation and systems change.

**Willowbrook Task Force.** The Commissioner personally meets on a quarterly basis with the members of this task force that continues to monitor OMRDD's activities in meeting the obligations specified under the Permanent Injunction. The task force includes representatives from the Consumer Advisory Board, New York Lawyers for the Public Interest, the New York Civil Liberties Union, and other family members and advocates for members of the Willowbrook Class.

**Advisory Council on Family Care.** Established in March 1991, this committee makes recommendations to the

Commissioner regarding the planning, administration, and management of the Family Care program. Both State and non-profit family care providers (referred to as agency-sponsored family care providers) serve on the Council, as well as DDSO directors, executive directors of nonprofit providers, the president of the Family Care Association, the chapter president of the National Adult Family Care Association, and the president of SANYS. Additional members come from the MRDDAC, the Statewide Committee on Family Support, and the Board of Visitors.

This pattern of consultation and collaboration with stakeholders ensures that OMRDD's planning goals address real opportunities for improvements in the system that is important to these stakeholders.

## 2003 OMRDD Constituent Forum Themes

During June and July of 2003 Commissioner Maul held eight Constituent Forums at locations around the state in order to solicit broad public input on services and supports available to people with developmental disabilities and their families and to develop strategies for addressing the need for services in the future. The forums also served to initiate the development of this comprehensive plan for 2006-2010. The forums gathered comments on customer satisfaction, quality improvement, consumer and family participation, community inclusion and systems change. One hundred and sixty people provided statements at the forums and 28 additional constituents sent written comments. More than three-quarters of the speakers were either people with developmental disabilities or their parents. The main themes to emerge from the statements are reported here. In Chapter 3 of this Plan, the themes from the Constituent Forums will be repeated as a framework for discussing OMRDD's current efforts and

future goals.

### **Self-Determination and Self-Advocacy.**

Self-determination was the most frequent topic cited by individuals with developmental disabilities and families. At virtually every forum, self-advocates and parents emphasized their desires to "have a life" and enjoy the freedom and control that people without disabilities take for granted. They spoke about the need to increase consumer and family influence on how nonprofit providers expend funds on their behalf. While recognizing the overall commitment of the state to self-determination and the progress that OMRDD has achieved in making it a viable option for people, they stressed the need for OMRDD, after several years of exploration and design activities, to press forward in realizing greater self-determination opportunities as a major component of systemic change.

Many speakers suggested that OMRDD conduct more frequent surveys of customer satisfaction in order to better identify how individuals with developmental disabilities and families feel about services and providers. Individuals with developmental disabilities and families see self-determination as a desirable alternative partly because of unresponsive or rigid features of the present service system, which they depict as dominated by provider interests. They want more flexibility in funding and more control over how money is spent. They requested that OMRDD develop supports that will enable them to lead more ordinary lives, have friends, earn money, enter into satisfying relationships, travel and fully participate in community life.

**Quality Staffing.** The importance of skilled and motivated staff, especially direct support professional staff, in delivering quality service was emphasized repeatedly, not only by self-advocates and parents, but also by providers. A growing consensus is emerging that recognizes that there is a strong connection between high

quality services and high morale among staff. A well supervised, trained, and stable workforce increases the likelihood that individualized services will be provided on a consistent basis. Many solutions to current staffing concerns were proposed, including salary enhancement, improved fringe benefits, creative marketing, educational and promotional opportunities, and recruitment from the ranks of students and parents. A number of speakers advocated for higher staffing ratios in some program settings to facilitate individual activities and community participation. Presenters noted that health and safety risks are reduced when there is continuity of staff within a service setting and all allocated positions are filled. Many speakers lauded OMRDD for its recognition of this issue over the past several years, noting its success at providing funds for salary increases in excess of 50 percent for direct support professional staff over the last decade. Additionally, speakers complimented OMRDD for using its website to successfully promote the recruitment of new employees.

Forum participants reported high rates of turnover and inconsistent performance in service coordination. Lack of service coordinator continuity disrupts formation of effective working relationships with individuals with developmental disabilities, families, and advocates. And it requires continuous reorientation of new staff to community resources and to consumer and family preferences and requirements. It was suggested that improved continuity of employment would allow service coordinators to improve their skills and become much more familiar with services and other system resources.

**Collaboration among Governmental Agencies.** A continuing note struck by presenters was the desire for greater OMRDD leadership in creating collaboration among government agencies and other parts of service networks. Several collaborative opportunities were mentioned, including partnership with:

- VESID or local schools, for vocational services;
- The Department of Health (DOH) and hospitals, for healthcare services;
- The Office of Mental Health (OMH), for behavioral healthcare;
- The Office of Alcoholism and Substance Abuse Services (OASAS), for substance abuse services;
- The SED and local school districts, for educational services; and
- Counties on a range of human service issues.

Commentators identified two priorities for collaboration with educational and mental health services. Individuals with developmental disabilities and families emphasized the necessity of greater coordination and planning at points of transition, as young children move into schools and then as young adults move from school into work or adult supports. Within adult services there were several recommendations regarding the need for more vocational training, both with respect to capacity and variety, improved transition-to-work planning and more diverse types of supported and competitive work opportunities. Self-advocates and parents criticized schools for lack of integration, provision of ineffective educational services and teachers who were not skilled in working with children with disabilities (especially children with low incidence disorders or complex conditions). Where feasible and appropriate, these advocates and parents called upon OMRDD to expand its work with school-aged children in order to bolster integration and develop specialized supports outside of the educational context.

The second area often mentioned was the need for increased variety and capacity in the delivery of services for people who have a dual diagnosis of mental retardation and mental illness, designed to address special needs presented by these individuals, as well as individuals with Autism Spectrum Disorders.

**Special Populations.** Several populations were cited as requiring specialized types of services from OMRDD and related agencies. They included people with dual diagnoses (needing mental health and developmental disabilities services), people with Autism Spectrum Disorders, people with developmental disabilities who are aging with dementia, and people with developmental disabilities of all ages who are medically frail. Speakers advocating for each group offered specific views of the types of services needed:

- For people with dual diagnoses, presenters called for more access to local, high-quality diagnosis and treatment services, as well as community supports, appropriate long-term care options beyond acute care hospitals, and crisis services.
- Families of children with Autism Spectrum Disorders reported that they needed improved access to comprehensive early intensive behavioral intervention and other comprehensive and consultative applied behavior analysis services as a part of local preschool and elementary school services.
- Families with adults with Autism Spectrum Disorders advocated for a range of community programs and specialized services that support more independent living and work, and skilled crisis intervention for adults with Autism Spectrum Disorders living with their families.
- Families and other advocates caring for people aging with dementia recommended that OMRDD develop the capacity to support these individuals in their current certified sites or at home in order to avoid their movement to nursing homes and other congregate settings.
- Similar approaches were recommended to address the needs of individuals with chronic medical conditions, by providing adequate supports in small community-based settings close to family.

**Person Centered Planning and Participation in Planning.** Self-advocates and families stressed the important contributions that person centered planning (PCP) processes have made to increasing individual and family member participation and influence over decision-making regarding service planning and delivery. Using a PCP framework, individuals with developmental disabilities and families feel they can exercise more control over the identification, individualization and design of supports and services, making services much more responsive to personal needs and preferences. PCP was identified by many commentators as a crucial component of a responsive service system.

**Transportation.** Improved specialized transportation and access to public transit was one of the most common needs identified. Speakers touched upon multiple aspects of this problem, often in the context of the need flexibility in the operation of programs. Several self-advocates noted that they had been able to or could obtain jobs, but had no means to get to work regularly. People trying to live independently complained that rigid or limited provider/paratransit vehicle schedules severely restrict their freedom to travel in the community, especially on nights and weekends and for social activities. Many transportation providers require individuals with developmental disabilities to schedule their travel days or even weeks in advance. Others decried long rides each day to and from certified program locations. Recommendations included improving paratransit systems, expanding rural transit access and making all transportation more available on short notice to address personal needs and interests.

**Access to Information.** Key concerns of individuals with developmental disabilities and families included: difficulty in obtaining sufficient information about the nature and location of services; difficulty in accessing or enrolling in services; and difficulty in obtaining information about

the quality of services offered by local providers. They suggested a variety of actions to address these concerns, such as:

- Increased outreach activities to inform individuals with developmental disabilities and parents about service opportunities and choices;
- The development of websites that provide this information to individuals with developmental disabilities and families;
- The involvement of service coordinators in community education of individuals with developmental disabilities and their families and advocates;
- Getting information to primary care physicians who are often a first contact for families with special needs children; and
- Collaborative efforts with parents and parent support groups.

**Community Inclusion and Community Building.** The need to improve supports for community participation and membership was a thread woven through the topics already noted. Individuals with developmental disabilities and families commented that present staff assignment and allocation practices limited opportunities for individualized community routines; that current individual planning processes failed to address the formation of memberships with community groups; and that some habilitation programs within the HCBS Waiver have not fully embraced community-based service delivery strategies.

**Work and Employment.** Self-advocates frequently underscored their desires for work and paid employment, and when employed, to work more often and for more hours. Most self-advocates viewed employment as an integral and indeed necessary component of more independent living. Families echoed these concerns, and both self-advocates and family members reported that identified employment opportunities were limited in most localities. Although speakers advanced few rec-

ommendations for increasing the supply of supported employment, transition to work and paid employment opportunities, it was clear from the frequent mention of work by self-advocates that this represents a major priority for enhanced services.

**NYS-CARES and NYS OPTS.** Self-advocates, families, and providers alike praised the NYS-CARES and NYS-CARES II initiatives as critical efforts to meet the residential needs of people with disabilities. NYS OPTS was also noted frequently by self-advocates and families as a critically significant vehicle for system change and enhancement.

## The Role of Local Government

As discussed in the earlier section on the CLMHD, mandates in Section 41 of the New York State Mental Hygiene Law require the development of comprehensive plans for programs and services for people with developmental disabilities. Both statewide and local plans are required, calling for a planning partnership among OMRDD, counties and boroughs, and dissemination of the plans to municipal governing bodies. OMRDD issues guidelines, approved by the CLMHD, that direct the counties in preparing their local government plans for that year. Each annual cycle of the local government plan process calls for a two-year projection of service gaps and priority service initiatives. This two-year planning framework encourages county input into decisions affecting both the current spending cycle and future OMRDD budget requests. OMRDD reviews and integrates input from local plans. Needs that are identified by many counties indicate emerging trends, which are often reflected in new service priorities and initiatives. The CLMHD also conducts periodic surveys of the counties and this information is factored into OMRDD strategic planning. The purpose of this planning strategy is to assist the service system at all levels to

adapt and respond to changing conditions. The local government plans develop an important picture of service needs and priorities from each locality's perspective.

**The Partnership Committee.** OMRDD and the CLMHD established the Partnership Committee in recognition of the need for a unified and comprehensive planning and resource allocation process covering the counties and the state. The committee developed *A Framework for Partnership-Based Planning* to improve the state and county planning process. It provides a comprehensive method for joint planning based on common goals.

**Substantive Themes.** The state/local planning process identified several major points of mutual concern for OMRDD and CLMHD, including particular services to children, adults, and people with dual or multiple diagnoses. Increased collaboration between local and state agencies in oversight of services was viewed as desirable. These concerns are summarized below.

**Services to Children.** Children with developmental disabilities and their families often are involved with more than one service system. Many county plans assert that the number of children identified with a developmental disability and a concurrent mental disorder is growing. Further, many of these plans point out that acute care for people with dual diagnoses is often non-existent and inpatient settings are often unable to provide services tailored for children with dual diagnoses. Additionally, counties stress that children with developmental disabilities often need:

- Access to medical specialists;
- Respite;
- Crisis intervention;
- Specialized services;
- Alternatives to foster care; and
- Recreation and after school programs.

**Services to Adults.** County plans often state that additional residential opportunities remain a continuing need for adults. They say that improvements are needed to make systems more responsive to emergency placement needs. Adults with dual diagnoses and elderly adults with developmental disabilities are particularly in need of housing. Accessible transportation remains a major issue. Counties have advised OMRDD that it would be timely to identify and disseminate findings regarding best practices for effective crisis management services and to implement integrated interagency crisis services.

**Services to People with Dual or Multiple Diagnoses.** Many county plans assert that the number of adults with developmental disabilities who also experience mental disorders appears to be increasing. Few counties have developed services to serve this group and services are not consistently available across the state. Counties have recommended to OMRDD that cross-systems collaboration on county and state levels is needed, with attention to the issue of primary responsibility for residential care, that consistent cross-training of developmental disabilities and mental health staff on county and state levels should occur, including training of professional and paraprofessional staff in local hospitals, and that related best practices in community dual diagnoses services need to be identified and disseminated.

# Priorities for Tomorrow



"People Having Coffee"

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## III. Priorities for Tomorrow

OMRDD's strategic direction has remained constant for many years. OMRDD strives to deliver supports and services that are varied, individualized and of high quality to people who are eligible to receive them. This is what individuals with developmental disabilities want. Ensuring that OMRDD accomplishes these strategic goals in a swiftly changing environment means undertaking large-scale and forward-looking programs that anticipate future needs and proactively shape the future by changing the way business is done. It also means persistent work on incremental improvements to the existing array of supports and services.

### **NYS-CARES II and NYS OPTS**

NYS-CARES II and NYS OPTS are current examples of bold, innovative ideas that will have broad impact on OMRDD's ability to meet its strategic goals in the years ahead.

**NYS-CARES II.** From its inception through March 31, 2004, the NYS-CARES program solved a huge problem for many persons with developmental disabilities and their families who were waiting in many cases for long periods for out-of-home residential services. It provided 9,134 people with places to live in the community and family support services for thousands more people waiting for help with residential needs. The close working relationship among families, advocates, the nonprofit provider community and New York State and the success of the initial NYS-CARES program were crucial factors in Governor Pataki's decision to introduce NYS-CARES II. This 10-year plan will develop additional services to meet family needs. Through a multiyear allocation process,

NYS-CARES II will provide an additional 1,900 new out-of-home residential opportunities, 600 new opportunities for in-home services and 370 new opportunities for day services. It will also provide additional funding for family support services beyond the State's initial commitment, to help individuals stay with their families as long as possible. An initial allocation of resources included in the plan has been completed. Future distribution of funding will acknowledge previous allocations and recognize the out-of-home waiting list using a fair-share formula. A broad spectrum of participants in OMRDD's system will participate in a mid-course evaluation of NYS-CARES II, at which time any necessary corrections to the initiative will be made. Having NYS-CARES II in place will enable OMRDD to keep its commitment to meet the demand for out-of-home residential services in a timely manner in the future.

Specific Comprehensive Five-Year Goals for NYS-CARES II are found in Chapter 4.

**New York State Options For People Through Services (NYS OPTS).** The major OMRDD program initiative during the Plan period will be NYS OPTS. This is a systems change initiative based on the Organized Health Care Delivery System (OHCDS) model permitted under federal Medicaid regulations. The Steering Committee established to guide the development of OMRDD's initiative gave the OHCDS approach the name "Options for People Through Services" or NYS OPTS. NYS OPTS will profoundly influence the variety, quantity, and quality of services in the OMRDD system.

NYS OPTS is a consumer- and family-driven method of providing highly individualized services to specific recipients by contract. Individuals with developmental disabilities and their families will play a critical role in shaping the services that are developed under various NYS OPTS contracts, which are to be developed in

order to meet individual customer and family requirements. Under NYS OPTS, the contractors will be nonprofit providers of service. Individuals and nonprofit providers can choose whether or not they wish to participate in this initiative.

The NYS OPTS initiative is being pursued to give people with developmental disabilities and their families increased choice and individualization in available services. OMRDD continually evaluates its service system to identify areas in need of improvement. Recent reviews, which include input from individuals with developmental disabilities, families, advocates, nonprofit providers and nonprofit provider associations, identified impediments to the provision of more individualized services. Through NYS OPTS, OMRDD will address these impediments and improve the quality of the service delivery system by enhancing community integration and attention to individual preferences. Individuals with developmental disabilities will gain by getting more individualized supports and services.

Under NYS OPTS, OMRDD will be the provider of record and will subcontract the provision of services to the nonprofit provider. It is anticipated that individuals and their families seeking services will participate not only in the design of their services, but also in the shaping of the NYS OPTS agreement between OMRDD and the nonprofit provider. The agreement will detail expectations for the program, including person centered service delivery, opportunities for enhanced community integration, and other quality outcomes, as well as funding and billing standards.

### **NYS OPTS Steering Committee**

To assist in the implementation of this major initiative and to ensure a collaborative direction, OMRDD organized a Steering Committee to advise OMRDD on NYS OPTS. This Steering Committee and its three subcommittees are comprised of a broad cross-section of system stakeholders. Steering Committee mem-

bership recognizes individuals with developmental disabilities, families, advocates, nonprofit providers, geographic areas, and types of programs and services. The involvement of the Steering Committee ensures that the NYS OPTS process is an inclusive one and that the ideas and preferences of stakeholders are given voice.

The Steering Committee has developed Guiding Principles for NYS OPTS. All proposals developed under NYS OPTS must meet and adhere to these principles. They will guide the selection of pilot project proposals and will constitute the standards for evaluating projects that are implemented. In addition, proposals must indicate how the plan differs from existing service models, how consumer choice will be increased, how services will be more individualized, the extent to which the program will use new or redesigned methods and processes to allow more efficient use of staff and other resources, and the extent to which cost savings or other productivity gains will result from the proposal.

### **Guiding Principles for NYS OPTS**

To accomplish OMRDD's mission and realize its vision of moving to an organized health care delivery system, OMRDD will be guided by the following principles to ensure that the needs of people with mental retardation and developmental disabilities and their families are met.

These are:

- Maximizing opportunities for **individual choice** through **person centered services**.
- Advancing **independence, inclusion** and individual and family **responsibility** throughout the system.
- Creating funding mechanisms that strengthen capacity to deliver **individualized services**.
- Preserving oversight systems to ensure the **highest quality services** for all individuals.
- Assuring that all providers promote the **health, safety** and **protection** of

individuals through compliance with the highest standards of operation.

- Improving **access** to needed services and supports for eligible individuals.
- Enhancing **flexibility** within the service system.
- Promoting **user-friendly** efficient and effective operations.
- Encouraging continued **participation** and open **communication** among all those involved in the system.

### **The Potential of NYS OPTS for Systems Change**

As NYS OPTS has unfolded, a variety of suggestions for improvements and refinements to the developmental services system have emerged. Some of these are captured in the following ideas for initiatives that could be undertaken using NYS OPTS:

#### **Individualized Day Services and Supports**

- Providing meaningful community inclusion and individualized services in small certified settings or totally within the community (i.e., "without walls").

#### **Individualized Residential Services and Supports**

- Creating residences, usually small ones, that are more responsive to the needs of individuals with developmental disabilities.
- Providing individuals who are aging, medically frail, behaviorally challenged and with psychiatric conditions with person centered residential alternatives to facility-based care.

#### **Blending Day and Residential Services and Supports**

- Offering seniors, people who are medically frail and others with special or changing needs a "life habilitation" option which would

eliminate what for them are artificial distinctions between residential and day services.

#### **Tailoring Services for Special Populations**

- Tailoring services for individuals in specific disability groups such as children, seniors, underserved members of minority groups, people who are hard to serve, individuals with developmental disabilities on the wait list, people who are medically frail, individuals with developmental disabilities with dual diagnoses and individuals with developmental disabilities in the forensic system.

#### **Targeting Services**

- Allowing individuals and families to work with providers in individualizing services in such areas as employment, respite care, school-to-work transition, continuing education, vocational readiness, family support services, training for parents with developmental disabilities, recreational opportunities and emergency services for domestic violence.

#### **Targeting Other Governmental Entities and Providers**

- Helping individuals and families that are dealing with a similar condition develop services that require collaborative planning, service provision cooperation, or training opportunities with other state or county agencies.

#### **Coordinating Services**

- Helping families demonstrate the value of service coordination enhancements such as: using providers as brokers for acute service navigation and bridge building; training for self-advocacy; helping individuals with developmental disabilities access their cultural community for greater integration; and enhancing opportunities for increased consumer rights.

### **Improving Staff Recruitment and Retention**

- Targeting activities that enhance recruitment and retention of staff from direct support to professional levels.

### **Improving Transportation**

- Creating transportation services that closely match the needs and desires of individuals with developmental disabilities for work and community integration.

### **Undertaking Other Activities and Initiatives**

- Targeting activities that enhance the lives of individuals with developmental disabilities, directly or indirectly, including the development and use of consumer satisfaction surveys, staff training and personal care aides.

Specific Comprehensive Five-Year Goals for NYS OPTS are found in Chapter 4.

## **Delivering Supports and Services That Customers Want**

In setting the agenda for the next five years, OMRDD began the process with the requests of its customers, as expressed by people with disabilities, their families, advocates and providers in the series of Commissioner's Constituent Forums held during the summer of 2003. It is important to note that people were pleased with the general direction of OMRDD efforts. Participants mostly suggested improvements to programs or initiatives that they considered to be heading in the right direction. The section that follows will directly address the comments and concerns expressed at the forums. The second section will address activities, mostly related to administrative systems, that OMRDD will undertake in order to accomplish its service-related goals. In both sections, a description of the current

status will be followed by identifying challenges in that area.

### **Self-Determination and Self-Advocacy**

To reiterate from Chapter 2, at the Constituent Forums, individuals with developmental disabilities and families made comments on self-determination that focused on the following points:

- They emphatically want the freedom and control that people without disabilities have.
- They want to increase consumer and family influence on how providers expend funds on their behalf.
- They called for more self-determination opportunities as a major component of systemic change.
- They asked OMRDD to conduct more frequent surveys of customer satisfaction.
- They are attracted to self-determination because of the potential to create more responsive and flexible supports.
- They want OMRDD to develop supports that will enable them to "have a life."

### **Current Status of Self-Determination and Self-Advocacy**

Service design and small-scale pilot projects on self-determination have gone on for several years. At this time, the pieces are in place for a healthy expansion in the number of people benefiting from self-determination and in the locations where self-determination is a viable opportunity. OMRDD and the self-advocacy community view self-determination as an option that should be available to everyone, although it is understood that not all people will choose to pursue control over their own budgets and services. Strong circles of support, advocates and skilled service brokerage can bring this option to people who need significant assistance with planning and budgeting. There are two varieties of self-determination. The first occurs when a person with disabili-

### **Key Challenge: Engaging Agencies in the Self-Determination Process**

*Many in the self-advocacy movement view self-determination as a systems change initiative. The opportunity for an increasing number of individuals with developmental disabilities to control their own individualized budgets has the potential to change the dynamics of how developmental disabilities services are provided. People will be able to seek services and supports from an expanding number of sources. Self-advocates, OMRDD and the network of nonprofit providers should collaborate to ensure that agencies can adapt to this new approach and use their considerable expertise to provide individualized supports that meet the specific needs and aspirations of the people who come to them for assistance.*

ties, his or her family and friends, a creative service coordinator and a flexible service provider work together within the existing framework to put together a unique package of supports and services that suits the individual. The second variety of self-determination occurs when a person uses the funding flexibility of the new Medicaid Waiver service, CSS, to achieve his or her desired outcomes.

OMRDD has established a pilot project using CSS. OMRDD has worked hard at developing a funding mechanism for self-determination that allows participant control of resources for services. The HCBS Waiver service of CSS allows a new degree of flexibility in the use of funds for self-determination. Participants can use CSS funding to purchase the supports and services they need to live in the community. Participants, with the assistance of their circles of support, manage the funds according to their approved plans. Fiscal Intermediaries (FIs) bill for services and supports provided by other vendors. They hold and disburse the funds at the participants' direction and in accordance with the participants' CSS budgets. FIs strengthen the person's role as the purchaser and manager of services and supports. Entities that want to be designated FIs must be nonprofit providers who are approved to provide HCBS Waiver funded services.

OMRDD is committed to getting CSS in place, making it work for individuals and making the flexible use of resources more widespread:

- Guidelines for the use of CSS are published and widely available. OMRDD now has a streamlined CSS proposal review process in place.
- There is at least one FI under contract to serve each DDSO.
- OMRDD has conducted training for service coordinators, advocates, family members and others who want to serve as "start-up brokers", that is, people who can assist self-advocates to pursue self-determina-

tion and develop their applications.

OMRDD has established a close working relationship with Self-Advocacy Association of New York State (SANYS), the organization for persons with disabilities who are interested in speaking up for themselves and acting to further their own interest. SANYS trains its members to have effective communications skills and encourages them to voice their concerns, which often center on the need for greater consumer control in planning for and delivering supports and for policies and practices that promote inclusion in the community. (This concern is discussed under "Inclusion and Community Building Activities" later in this chapter.) Self-advocates, working through SANYS, have held two retreats with leaders within the OMRDD service system. The retreats established a positive agenda for accomplishing self-advocacy goals and an even more effective working relationship with OMRDD and its providers.

Specific Comprehensive Five-Year Goals for Self-Determination and Self-Advocacy are found in Chapter 4.

### **Quality Staffing**

At the Constituent Forums, speakers made the following points about quality staffing:

- Skilled and motivated staff, especially direct support professional staff, are essential for delivering quality supports and services.
- Quality improves with a well trained, properly supervised, and stable workforce.
- Skilled and motivated staff are critical to the successful individualization of services, particularly in residences on evenings and weekends.
- Health and safety risks are reduced when there is continuity in staffing and all funded positions are filled.
- Service coordination suffers when there are high rates of turnover.

Proposed solutions included salary enhancement, improved fringe benefits, creative marketing, educational and promotional opportunities, and recruitment from the ranks of students and parents. A number of speakers advocated for higher staff ratios in some program settings to enable individual routines and community participation. Speakers lauded OMRDD both for its success at providing funds for a series of direct support professional salary increases, and the use of its website to promote the recruitment of new employees.

### **Current Status of Workforce Recruitment, Retention and Training:**

**Direct Support Professionals.** The recruitment and retention of direct support and clinical personnel is one of the most difficult issues confronting the entire human services and health care sectors. Fewer people are entering these fields at the very time when the demand for services is increasing, leading to recruitment difficulties. The nature of the work, although rewarding, is demanding. Many frontline workers have discovered that there is little incentive to remain in such taxing occupations. As a result, the best workers often choose other careers with better salaries, benefits and working conditions where they feel more valued as an employee. Employers continually invest resources into recruitment and training, with the expectation that these efforts will yield the more stable and experienced workforce necessary to provide high quality supports and services.

In recent years, OMRDD has made the recruitment and retention of the direct support professional workforce a high priority issue. Higher salaries are a key tool for recruitment and retention. In addition to salaries, improving worker incentives, training, career advancement and work environments are important factors in efforts to bolster the frontline workforce. To fully understand these issues, OMRDD has tapped nonprofit providers, direct

support professional staff, administrators, advocates, family members and individuals with developmental disabilities to serve as full-fledged partners. Collaboration has resulted in increasing visibility for recruitment and retention concerns. Over the past ten years, OMRDD has provided a 50.84 percent funding enhancement to its nonprofit providers, an increase well beyond the cost of living. Since the 2000-01 fiscal year, there has been an infusion of more than \$681 million into the service system that nonprofit providers can apply to direct support worker and nursing salary increases. OMRDD expects nonprofit agencies to use most of this money to increase direct support professional salaries.

Higher pay is not the only concern. On the recruitment side, OMRDD recently completed a \$4 million demonstration grant that successfully recruited and trained low-income workers for permanent positions in direct support. Follow up efforts will track the length of the new workers' tenures with the voluntary agencies that employ them. OMRDD has also dedicated a portion of its website ([www.omr.state.ny.us](http://www.omr.state.ny.us)) to employment information for people seeking direct support positions in the voluntary sector. This part of the website highlights the rewards of the field, including the opportunities to affect the lives of persons with developmental disabilities.

OMRDD has also launched a pilot on-line job bank ([www.greatjobsny.com](http://www.greatjobsny.com)) so nonprofit agencies can post vacancies in direct support and other jobs, and has helped market the website to employment intermediaries, such as high school guidance counselors, community college placement staff and One-Stop career centers. This system will allow job seekers to post a preliminary application for employment to specific positions.

In OMRDD's continuing efforts to enhance the training of direct support professional staff, the agency has recog-

nized the nationally validated Community Support Skills Standards (CSSS), a collection of 12 competency-based, on-the-job standards common to all direct support positions. The nonprofit provider associations have developed guidelines to incorporate the CSSS into nonprofit provider organizational structures such as staff training and job descriptions. OMRDD is working to use technology to increase training opportunities for direct support professionals and other staff. Projects to increase distance learning through both internet-based training sessions and video-conferencing are underway.

The quality of supervision experienced by the direct support professional is a key determinant of retention. OMRDD is organizing an effort by exemplary agencies that participate in the Consumerism Outcomes Management Plan Agency Self-Survey (COMPASS) program (discussed below under "Quality Assurance and Quality Improvement") to develop a training curriculum for site managers that should lead to improved supervisory practices throughout the system.

To develop a more comprehensive approach to recruitment and retention issues, OMRDD is establishing a statewide Direct Support Professional Advisory Committee, comprised of state and nonprofit provider representatives in direct support and other individuals. The committee will work on projects of benefit to the direct support professional.

Although criminal background checks for state employees in direct contact with individuals with developmental disabilities have been required for some years now, in 2004 legislation was passed and signed into law requiring background checks for employees of nonprofit providers. This measure promises to increase confidence in the integrity of the developmental disabilities workforce. OMRDD has established a Criminal Background Check Advisory Group to assist in the implementation of this new law.

**Service Coordinators.** Because forum participants mainly referred to service coordination in the context of the problems related to service coordinator turnover, the subject of service coordination is placed in this section of the Plan. Service coordination is an essential service, with great potential to help individuals achieve the outcomes they desire.

MSC, implemented by OMRDD on March 1, 2000, helps people with developmental disabilities gain access to necessary services and supports appropriate to their needs. Qualified service coordinators provide MSC. MSC uses a person centered planning process in developing, implementing, and maintaining an Individualized Service Plan (ISP) with and for a person with developmental disabilities. The MSC:

- Promotes the concepts of choice and consumer satisfaction;
- Enhances service coordinator and service provider accountability;
- Creates a more independent and professional workforce; and
- Strengthens protective oversight.

Currently, more than 60,000 individuals are enrolled in MSC statewide. It is noteworthy that a survey conducted with a sample of individuals and families who had received a residential opportunity through NYS-CARES indicated extremely high levels of satisfaction with the service coordination they had received.

Individuals with developmental disabilities have the right to choose their MSC provider and can readily change MSC providers. Participants may withdraw from MSC if they feel they no longer require the assistance of a service coordinator. All participants sign an agreement identifying the roles of the participant and the service coordinator /service coordination vendor in meeting the participants' goals.

There are strict qualifications and training requirements for new service coordinators

and service coordination supervisors. New service coordinators must attend a two-day Core training to acquaint them with the OMRDD service system and the role and responsibilities of the service coordinator. The training includes sections on person centered planning and valued outcomes. A person centered approach to planning is reinforced throughout the training. Local self-advocates teach a section of the Core training on self-advocacy that gives service coordinators a better understanding of what self-advocates want from their service coordinators, including an explicit list of "dos" and "don'ts" in supporting people with disabilities.

In addition to the Core training, all MSC service coordinators and service coordination supervisors are required to attend 15 hours of professional development annually. OMRDD has developed a series of required training modules. All MSC service coordinators must attend at least four of these required training modules within two years of their employment. Two of the required modules are "Introduction to Person centered Planning" and "Self-Determination/Self-Advocacy." Additional training can come from many sources including more than 25 courses offered by OMRDD through its Catalog of Training and Development Programs. The Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD) offers "Understanding Special Education: The Role of the Service Coordinator." Parent-to-Parent of New York State provides statewide training to families on how to access MSC and families' rights and responsibilities within the program. The Self-Advocacy Association of New York State, run for and by persons with developmental disabilities, trains other self-advocates on MSC.

OMRDD is using computer technology to assist MSC service coordinators with managing and reducing paperwork. A pilot project involving service coordinators using laptop computers for record-

keeping tasks has been expanded to all DDSO service coordinators. Project software allows service coordinators to complete ISPs, monthly notes and other documentation on laptop computers. A pilot to provide access for nonprofit provider service coordinators to connect with OMRDD service coordinators and other OMRDD staff has begun. The use of these technologies will allow for HIPAA-compliant, secure electronic communications between state and nonprofit provider staff, thereby reducing the production and handling of paper documents and saving time.

Achieving and maintaining high-quality service is important. To prevent potential conflicts of interest, staff who work with individuals in clinical and direct support roles are prohibited from providing service coordination to those same individuals. In addition, OMRDD's Division of Quality Assurance has a strict monitoring system of MSC. This includes interviews with individuals with developmental disabilities, family members and service coordinators. Service coordinators must complete a quarterly health and safety form for all MSC participants who reside in an OMRDD-certified setting.

To keep service coordination staff and service coordination providers informed about program development, OMRDD publishes the *Medicaid Service Coordination Technical Bulletin* on a quarterly basis. The *Medicaid Service Coordination Technical Bulletin* is also posted on OMRDD's website along with the *Medicaid Service Coordination Vendor Manual*, the compendium of rules and procedures. The *Manual* is updated regularly to provide the most current program information to service coordinators, supervisors, program administrators, individuals with developmental disabilities, their families and advocates.

Specific Comprehensive Five-Year Goals for Quality Staffing are found in Chapter 4.

### **Key Challenge: Increasing Staff Longevity**

*National studies, as well as OMRDD's own focus group research, support the notion that consumer satisfaction with services increases with less turnover of staff and as continuity of working with the same staff over time increases. This is especially true for service coordinators, where the length of the relationship among the consumer, family, and service coordinators is highly correlated with satisfaction. OMRDD and its MSC vendors are studying the reasons for excessive staff turnover in an attempt to identify successful strategies for keeping individuals with developmental disabilities and service coordinators together longer. There are administrative practices that support job consistency and longevity, not withstanding the turnover attributed to desired and unavoidable career development. Some practices involve improvements in workload management, supervision, technology and training. Both the state and voluntary sectors should develop methods of effectively implementing changes that will increase service coordinator longevity.*

**Key Challenge:**  
**Transitioning from School  
 to Work and Volunteering**

*Effective collaboration among the vast array of government departments, units, and programs designed to serve specific populations is essential for success. For example, people with developmental disabilities are entitled to receive services from educational, health, mental health, and social service agencies at the local, state, and federal levels. As children move into adolescence, it is important that transition planning occurs so that educational, vocational, and therapeutic goals can be established early and needed supports can be coordinated throughout the transition period and beyond. This coordination requires that school districts work proactively to involve OMRDD, VESID, and other agencies to ensure that individualized supports and services for employment, volunteering, and other adult activities will be available when they are needed.*

## **Collaboration Among Governmental Agencies**

Presenters at the Constituent Forums called for greater OMRDD leadership in creating collaboration among state and local government agencies and other parts of service networks. Commentators called for:

- Collaborations with educational institutions and mental health services.
- Greater coordination and planning when children transition into schools and when they transition from school into work or adult supports.
- More and higher quality supported and competitive work opportunities.
- Expanded OMRDD work with school-aged children outside of the educational context.
- More services for individuals with dual diagnoses and with Autism Spectrum Disorders.

### **Current Status of Collaborative Efforts**

**Children's Services.** Effective inter-organizational cooperation is essential in assisting children with disabilities. This is because children's service needs span several state agencies and local entities, with OMRDD, DOH, SED, local school districts and other organizations involved. To give children the best chance to receive appropriate services, OMRDD participates in several interagency and multiorganizational councils and committees devoted to children's issues. OMRDD participated in the Early Intervention Coordinating Council Taskforce on Transition. This panel assisted DOH in developing and reviewing informational materials for parents, providers and early intervention program officials. OMRDD also participates in a committee devoted to the transition of students with developmental disabilities from school to adult opportunities. Following a recommendation of the MRDDAC, OMRDD mails a notice to parents of students with developmental disabilities reminding them about federal and state transition

planning requirements. More than 2,300 notices have been mailed to date.

**The Americans with Disabilities Act and the Olmstead Decision.** The State of New York enacted a law establishing the Most Integrated Setting Coordinating Council (MISCC), whose actions are guided by the principles set forth under the *Olmstead* decision (see below) to empower individuals with disabilities to live more independently. New York State agencies represented as members of the Council are the: OMH, DOH, the State Office for the Aging (SOFA), OMRDD, SED, OASAS, Division of Housing and Community Renewal (DHCR), Department of Transportation (DOT) Office of Children and Family Services (OCFS), and CQCAPD.

Some background: In June of 1999 the Supreme Court of the United States affirmed a judgment in the *Olmstead v. L.C. and E.W.* suit, which upheld Title II of the Americans with Disabilities Act (ADA) and applied it to access to services. Title II of the ADA proscribes discrimination in the provision of public services and specifies, among other things, that no qualified individual with a disability shall, because of the disability, be excluded from participation in, or be denied the benefits of, a public entity's programs or activities. Congress instructed the Attorney General to issue regulations implementing Title II's discrimination proscription. One such regulation, known as the "integration regulation," requires a public entity to administer programs "in the most integrated setting appropriate to the needs of qualified individuals with disabilities (28 CFR § 35.130[d])." A further proscription, called the "reasonable-modifications regulation," requires public entities to "make reasonable modifications" to avoid "discrimination on the basis of disability," but does not require measures that would "fundamentally alter" the nature of the entity's programs.

By a Presidential Executive Order, "the

federal government must assist states and localities to implement swiftly the Olmstead decision," to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment and to participate in community life.

**Housing Assistance.** OMRDD has long collaborated with other entities to increase generic housing opportunities. During the past four years more than 72 individuals and families became homeowners through the cooperative efforts of OMRDD and the State of New York Mortgage Agency (SONYMA) in the Home of Your Own Program. OMRDD has also received a \$400,000 HOME grant through the state DHCR to assist more than 20 individuals and families in becoming first-time homebuyers. Technical assistance to provider agencies has helped them generate over \$40 million in capital financing through DHCR and United States Division of Housing and Urban Development (HUD) programs, including HUD Section 811 grants and Low-Income Housing Tax Credits. OMRDD initiated a statewide collaboration with DHCR that brings together OMRDD provider agencies, regional transportation planners and developers of affordable housing to support the development and marketing of affordable and accessible housing to individuals and families with developmental disabilities. OMRDD is also assisting the DDPC in creating a statewide web-based registry of adaptable and accessible rental units.

Specific Comprehensive Five-Year Goals for Collaboration among Governmental Agencies are found in Chapter 4.

## Special Populations

Forum participants cited several populations as requiring specialized services from OMRDD and related agencies. They included:

- People with dual diagnoses (those needing mental health and develop-

mental services);

- People with Autism Spectrum Disorders;
- People with developmental disabilities who are aging with dementia; and
- People with developmental disabilities of all ages who are medically frail.

Advocates for each group offered very specific views of what types of services are most needed. They included:

- For people with dual diagnoses, presenters wanted more local diagnostic and treatment services, community supports and appropriate non-hospital, long-term care options, and crisis services.
- Families of children with Autism Spectrum Disorders asked for more comprehensive early intensive behavioral intervention and other applied behavior analysis services.
- Families of adults with Autism Spectrum Disorders advocated for specialized services that support more independent living and work and for skilled crisis intervention for adults with Autism Spectrum Disorders living with their families.
- Families and others caring for people aging with dementia wanted OMRDD to develop the capacity to support these individuals in their current residences.
- Advocates for individuals with chronic medical conditions recommended supports available in small community-based settings close to family.

## Status of Actions Regarding Special Populations

**Aging.** Governor Pataki's Project 2015 initiative and the Commissioner's Task Force on Aging guide OMRDD in providing services to aging individuals with mental retardation and developmental disabilities. OMRDD is committed to providing individualized services across

**Key Challenge: Crisis Intervention for People with Dual Diagnoses**

*OMRDD and residential providers need to consider the array of crisis and behavioral services needed to sustain a large and dispersed residential system. Preferred practice today involves stabilization and maintenance in the current community-based setting whenever possible. Staff from the mental health and developmental disabilities systems must be cross-trained and teamed to collaborate effectively using the best contemporary therapies and interventions. Shifting the focus to prevention rather than crisis intervention through increased understanding and use of positive approaches, functional communication systems and environmental enhancements will be another critical strategy in the future.*

the life span. Aging individuals with mental retardation require opportunities to "successfully age in the community." OMRDD's Center for Aging supports collaborative action in this area. OMRDD uses "Aging with Dignity" (AWD) training to promote integration into the existing aging network. The 2004-2005 AWD training theme focused on Alzheimer's disease and developmental disabilities. OMRDD, in collaboration with NYSARC, conducts statewide training in End-of-Life Care (EOL). A DDPC grant supporting an EOL care training project, completed in 2003, focused on end-of-life care issues facing providers caring for older adults with mental retardation and developmental disabilities. Subsequently, DDPC funded an 18-month Train-the-Trainer End-of-Life Care Project that aims to prepare 250 trainers. OMRDD provides technical assistance and training statewide on aging topics. In addition, OMRDD has a contact person for aging in each district who works with local coalitions of public and voluntary agencies interested in people who are aging with developmental disabilities. OMRDD supports the annual statewide training efforts of the Third Age Committee, a group of nonprofit providers of services to seniors with developmental disabilities.

**Dual Diagnosis.** OMRDD continues to work on services for dually diagnosed individuals. There are about 300 Multiply Disabled Unit (MDU) institutional residential opportunities in the OMRDD system serving individuals with diagnoses of developmental disability and mental illness. From April 2002 to April 2004, approximately 40 individuals transferred from OMH psychiatric centers to OMRDD-certified community or institutional settings. These transfers are the result of specific state budget language and resources intended for such transfers. Of an additional 84 referrals identified by OMH as of April 2004, almost a third were not psychiatrically stable, another third were in the screening process for OMRDD eligibility and psychiatric stabili-

ty, and the last third were stable and ready for either institutional or community placement, but their placements were delayed due to limited residential capacity available to people with a dual diagnosis.

Specialized knowledge, ability to access services from multiple systems (OMH, OMRDD, Social Services, etc.), flexibility of funding, and networking of state, county and local provider agencies are the essential components in developing services for people with dual diagnoses. Beginning in 2003, DDPC, in consultation with OMRDD and OMH, provided start-up funding for two years to create three Regional Centers for Dual Diagnosis. The consortia of providers that received these grants spent the first year developing a curriculum based on a DDPC product, *Dual Diagnosis: Mental Health/Mental Retardation, A Reference Guide for Training*. The second year of the DDPC funding continued this training effort and established local or regional networks of state, county and voluntary service providers to foster planning and communication across the service system and to explore ways to continue the work of the Centers after DDPC funding ended. The DDPC also established a website ([www.centersfordualdiagnosis.net](http://www.centersfordualdiagnosis.net)) for sharing information about this population and the people who serve them.

**Children with Medical Conditions.** OMRDD manages a specialized Medicaid Care-at-Home (CAH) Waiver for children under the age of 18 who have a developmental disability and a pervasive medical condition. The CAH Waiver allows parents to keep their children at home rather than resorting to institutional placement. OMRDD operates three separate model waivers for the same population, two with caps of 200 and one with a cap of 100 children. With the capacity of 500 there was a substantial waiting list. In fall 2005 OMRDD was notified of approval for an additional 100 opportunities. With the increased capacity to 600, OMRDD anticipates operating with a manageable waiting

list.

**Autism Spectrum Disorder.** Recently, OMRDD entered into a unique relationship with a private philanthropic foundation, the FAR Fund, which is interested in promoting improved services in the New York City region for adults with Autism Spectrum Disorder. The fund provides substantial multi-year grants to three agencies in New York City committed to designing person centered supports and services for ten individuals with Autism Spectrum Disorders whom they already serve. This three-year project will create additional agencies in the downstate region with person centered planning expertise and will develop strategies for working with people with Autism Spectrum Disorders that can be shared as best practices with families and other service providers.

**Behavioral Crises.** To ensure delivery of quality services, staff must be trained to deal with behavioral crises. In 1998, OMRDD distributed an extensively revised training program, Strategies for Crisis Intervention and Prevention-Revised (SCIP-R) to DDSOs and nonprofit provider agencies. SCIP-R is designed to prepare staff to prevent crises and to effectively intervene when behavioral crises occur. The revised material emphasizes positive approaches to behavior control that prevent incidents from escalating to the point where "hands-on" approaches become necessary. Since 1998 there has been extensive SCIP-R training in DDSOs and provider agencies for the thousands of staff providing services to people with developmental disabilities. During this past year, updates to the SCIP-R curriculum included a section on dealing with challenging passenger behaviors during transportation in cars, vans or buses. Further refinements underway include training guidelines for using SCIP-R with children. These improvements to the SCIP-R curriculum are the result of collaboration and discussion with DDSOs and nonprofit providers.

**Multicultural Populations.** One-third of individuals with developmental disabilities served by OMRDD are from federally defined minority groups. In addition, immigration continues to grow, both in total numbers and in the variety of ethnic groups represented. Urban centers, especially New York City, have scores of cultural and ethnic communities that must be afforded equitable access to the developmental disabilities service system. Adequately serving these groups will be an increasing challenge in the years ahead and OMRDD must make the development of culturally appropriate services and supports for many different groups a high priority. To enable small providers and new nonprofit providers to develop effective and efficient business practices, OMRDD offers fiscal training to these nonprofit providers. Consultants have been made available to provide training on person centered philosophies that respect cultural uniqueness. OMRDD is currently developing a specialty module for MSC staff on Cultural Competence.

The Multicultural Provider Network will continue to be a pivotal resource in enhancing awareness and understanding of multicultural needs. OMRDD is proud of its accomplishments in supporting multicultural providers over the last several years. The range of services provided by multicultural organizations has already been broadened in scope considerably. In Broome County, the Urban League sponsors a highly successful fully integrated summer youth program that helps children better understand other peoples' cultures. In Rochester, collaboration efforts among the Multicultural Agencies United for Developmental Disabilities (MAUDD) have resulted in parent institutes on special education services. These institutes are highly acclaimed and in process of replication at other sites. In Brooklyn, local Multicultural Provider Network sponsorship of targeted trainings on budgeting, audits, proposal writing, and funding opportunities contributed to suc-

### **Key Challenge: Expanding Access to Person Centered Planning**

*It has been demonstrated that person centered planning enhances the lives of many people with developmental disabilities. A continuing challenge will be to make person centered planning available to more people with developmental disabilities over the coming years. Nonprofit providers have increased understanding and appreciation of person centered planning and of how individuals with developmental disabilities, families and staff benefit from this approach. OMRDD and its nonprofit provider sector must do even more to recognize the value that is added by utilizing a person centered approach and should consider methods to more fully integrate these practices into their supports and services.*

cess in garnering three grants for member agencies. In addition to providing technical assistance to providers, the Brooklyn Network publishes and distributes a newsletter quarterly. Across the state, communities and other state agencies are now more aware of the services that multicultural agencies provide right in the communities where people live. These examples represent a few of the successes of OMRDD partnership with multicultural providers, but the challenge remains to continue to meet the growing needs of these populations during the Plan years.

Specific Comprehensive Five-Year Goals for Special Populations are found in Chapter 4.

### **Person Centered Planning and Participation in Planning**

Self-advocates and families:

- Credited person centered planning (PCP) processes with increasing individual and family member participation and influence on decision-making regarding service planning and delivery; and
- Identified PCP as a crucial component of a responsive service system.

### **Status of Person Centered Planning**

OMRDD's long-standing commitment to the Individualized Service Environment (ISE) can now best be expressed as a desire to use a person centered approach to establish an individualized supports and services plan for each person. PCP puts the person squarely in the center of the planning process, bases services and supports on personal capacities, needs, and interests, and attempts to use typical community supports and services whenever possible. Experience has shown that designing a residential environment and schedule of weekly activities around the capacities and interests of people can dramatically reduce stress, isolation, anxiety and challenging behaviors. OMRDD is now committed to using person centered

approaches. Some of the principles that are used in PCP include:

- Encouraging the formation of a circle of support, selected by the person or his or her representative, to assist in planning, decision making, safeguarding and health promotion.
- Developing a positive future vision for each person that motivates the person and his or her circle, and drives the service and support plan.
- Focusing on relationship and community building to strengthen the network of supports and increase opportunities for community membership and full citizenship.
- Accessing generic resources found in most communities such as health services, public transportation and religious organizations.
- Contributing to the community through volunteering, working and joining clubs or civic organizations.
- Minimizing reliance on expensive forms of transportation by making more neighborhood connections.
- Finding competitive employment rather than relying on day programs that limit training to self-help skills.
- Learning how to self-advocate for assistance instead of depending on professionals.
- Encouraging the management of one's own plan of services through self-determination, which allows for greater independence in decision making and more fiscal control.

Over the past decade, OMRDD has invested heavily in staff training and development activities associated with PCP and inclusion. Its *Catalog of Training and Development* offers many classes in Introductory and Advanced Person Centered Planning, Community Inclusion, Self-Advocacy/Self-Determination, Day and Employment Services, Individualized Housing and Individualized Service Planning. Workshops are offered each year. Of special note is a series of men-

toring workshops on Personal Futures Planning given by Dr. Beth Mount, one of the originators of PCP and a consultant to OMRDD on PCP projects.

OMRDD has promoted the individualization of services, the person centered approach, and inclusion in the community through a variety of initiatives. OMRDD conducted six workshops statewide on Innovative Day and Employment Supports and Services for Individuals with Disabilities, more commonly known as "Day Programs Without Walls." This was done in collaboration with three regional Person Centered Planning Networks, each of which include DDSO staff, nonprofit provider agencies, individuals with developmental disabilities, self-advocates, family representatives and policy makers. Nearly 1,000 people participated in these events.

OMRDD staff published studies from the Willowbrook Futures Project which evaluated the effectiveness of formal PCP in promoting inclusion. Investigators gathered data on changes in services for a group of Willowbrook Class individuals with developmental disabilities who moved from New York City developmental centers to community living. Nineteen of the 20 individuals with developmental disabilities in the person centered planning group achieved community residential inclusion. Only five individuals with developmental disabilities from a similar group who received traditional individual service planning moved to the community. Contributing to the success of the project were:

- Formal staff training in person centered planning;
- Flexible financial assistance (up to \$5000 per person) to supplement community transition activities; and
- Cooperation between multiple partners in the planning and implementation of individualized services and supports.

Specific Comprehensive Five-Year Goals for Person centered Planning and Participation in Planning are found in Chapter 4.

## Transportation

Participants at the forums identified improved specialized transportation and access to public transit as important needs and made the following points:

- Individualized supports and services often depend upon transportation.
- Jobs are being declined for lack of means to get to work.
- Provider or paratransit vehicle schedules severely restrict freedom to travel in the community, especially on nights and weekends for social activities.
- Many transportation providers require individuals with developmental disabilities to schedule their travel days or even weeks in advance.
- People with disabilities often have to endure long daily rides to and from certified programs.

## Status of Transportation Activities

OMRDD recognizes that transportation issues loom large with many individuals with developmental disabilities and their families. As individuals participate more in their communities, transportation needs frequently become more complex. Transportation is often provided by generic agencies, public transportation companies, family and friends all of whom are outside the direct control of OMRDD. Improving individualized transportation opportunities is indeed a challenge for the system.

OMRDD does, however, support a variety of transportation initiatives. Several DDSOs in urban areas have instituted travel-training programs that encourage the use of public transportation for individuals who can use it. For others, OMRDD provides or arranges transportation services that move individuals closer to independence, providing support as needed and challenging individuals to fur-

## **Key Challenge: Inclusion Requires Transportation**

*As people with all levels of disabilities attempt to live inclusive and contributory lives in the community, transportation becomes an increasingly vital service that many still cannot obtain. OMRDD can never solve this problem alone. The solution will come from mobilizing and coordinating transportation resources from a variety of systems to support people with disabilities and by acknowledging the need to address the nation's general transportation challenges.*

**Key Challenge: Assuring awareness of and access to Supports and Services**

*While technology is vastly improving the amount of updated and accurate information available to the general population, OMRDD also relies on more traditional methods of communication to assure that all its constituents have access to information to improve their quality of life. OMRDD must continue to develop effective and efficient means of providing information to assure that everyone has access to the information they need, regardless of their means for obtaining it.*

ther develop travel-related skills.

OMRDD has instituted a statewide van safety training program for drivers. Also, OMRDD updated policies on vehicle management and transportation support safety to improve transportation services. As a component of this initiative, OMRDD disseminated safety information on the rollover risks inherent with the use of 15-passenger vans and identified the safest alternative within this class of vehicles.

New specifications for wheelchair van design have resulted in the availability of safer and more attractive vehicles for use in community residential and day programs. Now more individuals with disabilities can get to community settings and they can do so without the stigma of traveling in an obviously institutional bus. Vehicles procured with OMRDD assistance have these specifications written into the contract language.

OMRDD participates with the NYS DOT in administering the Federal "5310" grant program for the acquisition of vehicles. This allows voluntary agencies to acquire vehicles with 80 percent federal funding. This process involves collaboration among OMRDD, voluntary agencies, NYS DOT and local metropolitan transit authorities.

Specific Comprehensive Five-Year Goals for Transportation are found in Chapter 4.

### **Access to Information**

Individuals with developmental disabilities and families were concerned with the difficulty of getting information about available services. Suggestions for improving this included:

- Increasing outreach activities at the grassroots level to inform individuals with developmental disabilities and parents.
- Enhancing the OMRDD website to provide additional information.

- Involving service coordinators in community education initiatives, in order to inform people about services available through the OMRDD system.
- Providing information to primary care physicians who are often a first contact for families with special needs children.
- Establishing collaborative efforts with parent and parent support groups.

### **Status of Initiatives to Improve Available Information**

OMRDD has operated a service directory as part of its website for more than five years. Citizens can learn about available services and locate the nonprofit providers that offer them. Through enhanced Geographical Information System (GIS) technology, an individual may conduct a search based on local address, zip code, or county to locate the main offices of nonprofit as well as New York State service providers close to where he or she lives. Through links built into the system, they can leave the OMRDD website and go directly to the nonprofit providers' websites to receive further information. This project was awarded a **Best of New York** designation from the Center for Digital Government, which recognizes excellence and outstanding contributions in the area of information technology across the country.

Efforts to enhance the Map and Resource Directory on the OMRDD website continue. An internal OMRDD Web Review Committee produced a report in February of 2004 that recommended a number of improvements to the OMRDD website. Many of the recommendations from that report have already been implemented.

A group of OMRDD service coordinators and other staff are pilot testing a geographic information system based (GIS-based) system to assist families and individuals with developmental disabilities who are looking for out-of-

home residential opportunities. Through this secure application, state and nonprofit staff, working with family members, are able to see housing options that may be available, where they are located, and other helpful information about the particular location. This system, designed for authorized users only, protects the confidentiality of the individuals living in the residences while it provides needed and helpful information for prospective residents and their families. OMRDD has set aside a portion of its website ([http://www.omr.state.ny.us/hp\\_fss\\_all.jsp](http://www.omr.state.ny.us/hp_fss_all.jsp)) to further define and explain the family support services delivery system, its benefits and other useful information.

Specific Comprehensive Five-Year Goals for Access to Information are found in Chapter 4.

## Community Inclusion and Community Building

Participants at the constituency forums called for improved supports for community participation and membership and made the following specific points:

- Staff assignment practices limit opportunities for individualized community routines;
- Current individual planning processes often fail to address the formation of memberships with community groups; and
- Many habilitation programs have not fully embraced community-based service delivery strategies.

## Status of Inclusion and Community Building Activities

OMRDD, working through its New York City Regional Office (NYCRO) and several DDSOs, has sponsored the Leadership Institute for Direct Support Professionals, called "Everyday Heroes." The program was designed to enrich the experiences of direct support professional staff involved in community inclusion activities by having them learn from the experiences of selected state and nonprofit employees

who are direct support professional leaders. Participants of the Leadership Institute identified 12 themes that express positive direct support qualities and activities which promote person centered attitudes and community inclusion. Participants are now involved in conveying these themes to other direct support professionals within their own agencies and beyond. Direct support professional leaders will continue to participate in the Institute, and the curriculum is being replicated across New York State. Everyday Heroes has been presented with the nationwide **Moving Mountains Award** by the Research and Training Center on Community Living at the University of Minnesota in partnership with the National Alliance for Direct Support Professionals.

OMRDD and self-advocates have joined in a number of activities to promote individualized services and supports. The Day Programs Without Walls initiative brought together nonprofit providers and self-advocates to discuss issues around person centered approaches to work and quality of life. Teams of DDSO staff, nonprofit provider employees, and self-advocates are also working with several large ICFs/DD on a project called "Real Choice" that is using person centered planning and peer mentoring to downsize larger facilities by offering the opportunity to plan for more individualized living. As discussed in Chapter 2, the two retreats that brought together self-advocates and OMRDD leaders in June of 2002 and September of 2004 were very productive in creating a practical inclusion agenda that will promote appropriate inclusion activities. In addition, OMRDD is working with SANYS to create a Community Participation Task Force as another vehicle to promote community building activities.

Today, young adults with mental retardation and other developmental disabilities often leave home with the intention of becoming included in mainstream society.

### **Key Challenge: Identifying Nearby Community Connections**

*There is a growing recognition that understanding each person's capabilities and interests is not enough. One must explore the community available to that person and identify key assets and resources that lie within reach. Such "community mapping" that identifies opportunities within walking distance or a short ride from home or work should become a standard practice. Once opportunities for community connections are identified, relationships must then be nurtured in order to fully integrate a person into that community.*

### **Key Challenge: Supporting Careers**

*For some people with developmental disabilities who are now employed and/or volunteering successfully in their communities, a critical challenge for the future will be to go beyond part-time jobs that require limited skills, and build meaningful "careers." Careers are characterized by a long-term commitment to a type of work or valued community role that can sustain a person's interest, generate respect in the eyes of community members, lead to personal growth, and move the person toward economic self-sufficiency. Through the use of person centered planning, individualized vocational training and supports, and entrepreneurial business models, some self-advocates are realizing exciting new opportunities that lead to recognition in their neighborhoods for what they are doing now rather than for how they may have been labeled in the past. The challenge will be to replicate these successes around the State.*

But making connections within the community is not always easy. OMRDD has obtained a grant from the federal Administration for Developmental Disabilities, under its Projects of National Significance program, to address this issue. OMRDD's grant project is designed to reach out to grassroots organizations in selected communities in New York State and to enlist them in helping people with developmental disabilities become active participants in neighborhood organizations. Specific Comprehensive Five-Year Goals for Community Inclusion and Community Building are found in Chapter 4.

### **Work and Employment**

Speakers at the forums frequently talked about work and made the following points:

- Self-advocates want to work;
- Employment is a necessary component of more independent living;
- Employment opportunities are limited in most localities; and
- Work is a major priority for service enhancement.

### **Status of Employment Initiatives**

**Supported Employment.** In an effort to create a system sensitive to individuals' support needs, OMRDD converted supported employment to a fee-for-service model funded through the HCBS Waiver Supported Employment service. The methodology adopted for this conversion established six enhanced fee levels for two regions of the state (New York City and the rest of the state), effective October 1, 2001. The new fee structure is intended to provide incentives for the development of more and higher quality supported employment opportunities.

During this conversion process, OMRDD identified approximately 1,500 individuals in OMRDD funded supported employment programs who did not meet OMRDD eligibility criteria. OMRDD staff worked with the Division of Budget

(DOB) and the SED to develop a seamless process that would transfer these individuals to SED's VESID Office. The transfer of funding responsibilities took place on July 1, 2003 without any impact on services to these individuals.

In 2002 OMRDD was a co-winner of the Citizen's Budget Commission **Prize for Public Service Innovation**. This was given to OMRDD for developing an internet Claiming and Billing System that automated the supported employment reimbursement functions previously managed through contracts. The reporting system allows nonprofit providers to submit claims for payment via the internet to OMRDD on a monthly basis and receive payment much more quickly. The new system ensures accurate and timely reporting and creates greater accountability and autonomy for nonprofit providers.

**Medicaid Buy-In.** On July 1, 2003 the Medicaid Buy-In for Working People with Disabilities (MBI-WPD) took effect in NYS. The MBI-WPD will make Medicaid coverage available to employed people with disabilities between 16 and 64 years of age whose income from work previously would have disqualified them for coverage. OMRDD staff worked collaboratively with other state agencies on this project and has been conducting training to inform individuals and nonprofit providers of this new opportunity that allows individuals with disabilities to increase their earning levels without jeopardizing medical benefits.

**Self-Employment.** DDPC funded the continuation of OMRDD's Supported Self-Employment grant. The project provides technical assistance to persons who are interested in starting their own businesses. It also enables OMRDD to provide specialized training and technical assistance to families and providers involved with these people. This project has developed a vocational option previously unavailable to persons with developmental disabilities.

Specific Comprehensive Five-Year Goals for Work and Employment are found in Chapter 4.

### **Family Support Services**

OMRDD has long recognized the importance of family support services as an essential tool for achieving an important system outcome - that is, to have children grow up with their parents in their family home. OMRDD understands how difficult it is for parents to provide the necessary supports for an individual with developmental disabilities, as well as provide financial and emotional supports for other family members and themselves. OMRDD's commitment to family support can be seen in the expansion of family support services and in the growth in spending for these services over the last fourteen years (see chart on page 14). These services have helped many families successfully care for their family members at home.

### **Other Improvements in Service Quality**

OMRDD continues to improve its ability to listen to its customers and respond to their desires. However, OMRDD cannot always respond to customers' desires because the type and quality of services and supports are affected by the administrative systems OMRDD uses to deliver services. The workings and effects of administrative systems are not always clear to individuals with developmental disabilities and other stakeholders. It is OMRDD's obligation to pursue large- and small-scale changes in the administrative systems that will facilitate the delivery of the kinds of supports and services that customers want.

### **Quality Assurance and Quality Improvement**

OMRDD expects all staff engaged in state and nonprofit provider operated programs to deliver quality services and to strive for improvements in quality. Quality

cannot be taken for granted, but must be monitored. The main guarantor of quality services in the system is OMRDD's Division of Quality Assurance, which surveys programs and takes assertive action against substandard operations.

OMRDD certifies programs only after determining that individuals with developmental disabilities served by them are safe, satisfied, and receiving appropriate services. Over the past seven years, the survey focus has changed from a detailed, paper-oriented regulatory review to an outcome-based, consumer satisfaction review process. OMRDD's efforts to improve quality assurance are directed at gathering accurate consumer satisfaction measurements and using those data to enhance program operations.

OMRDD periodically holds Consumer Forums throughout New York State for individuals with developmental disabilities, family members, advocates and other interested parties. At these forums OMRDD explains how the quality assurance system works and receives suggestions from individuals with developmental disabilities and others on improving the survey process.

**COMPASS.** This alternative approach to program certification seeks to enhance the quality of program services by focusing on internal assessment rather than external review. COMPASS agencies have demonstrated a high level of excellence in service provision and agency management. Each COMPASS agency makes a continuous effort to establish and maintain effective systems for identifying and correcting problems internally and for enhancing consumer satisfaction. COMPASS agencies are asked to participate in various OMRDD initiatives. These include serving on committees, being trainers for OMRDD's Board of Directors training initiative, and facilitating networking among various provider agencies.

### ***Key Challenge: Reaching Out to Families***

*OMRDD will continue to reach out to families seeking family support services and will continue to provide services and supports that are responsive to the changing needs of these families.*

**Key Challenge:  
Incorporating Consumer  
and Family Input Into  
the Measurement of  
Performance and  
Satisfaction.**

*Modern principles of quality require human service systems to move beyond the monitoring of minimal regulatory compliance. The focus is now on motivation of providers to achieve measurable quality of life outcomes. People's satisfaction with the services they receive is important not only to the success of the program itself, but to assuring that services actually meet people's needs. Service satisfaction is correlated with the impact the services have on how people live and what they are able to do. A key attribute of the most effective and highly rated agencies is their ability to produce the outcomes that people and families want. Program monitors need to better develop methods of gaining input from individuals with developmental disabilities and family members about what "quality" means to them, and then incorporating that input into the design of assessment approaches that measure service quality.*

**Board of Directors Training.** OMRDD implemented its Board of Directors training program for the governing boards of nonprofit provider agencies in 2004 after a successful pilot in 2003. The key method used in the training sessions is the discussion of realistic cases. Board training is coordinated by OMRDD Central Office and is provided to new nonprofit agencies, and nonprofit agencies experiencing programmatic or fiscal difficulties. Trainers include senior OMRDD staff, DDSO staff and COMPASS agency staff. Feedback from participants indicates that it is extremely beneficial in providing helpful information and in building governing teams.

**Improving Survey Practices.** Composed of health care professionals from within OMRDD, the Health Care Committee was established in 2000. The committee strives to ensure consistency of survey methods across the state regarding health care through technical assistance, training and consultation. The Willowbrook Consent Decree established a class of individuals with developmental disabilities with specific rights and OMRDD continues to work with the Willowbrook parties to improve the oversight of programs and services for Willowbrook class members. OMRDD has also developed a joint fiscal and program review to provide more effective oversight of Article 16 clinics. All OMRDD surveys emphasize consumer and family satisfaction with services. But the emphasis on satisfaction with services is especially prominent in the review of MSC. Satisfaction is determined through consumer, family and advocate interviews using a standard questionnaire. OMRDD's policy is to accept direct complaints from the community about diminished services to individuals with developmental disabilities. Complaints are investigated and problems resolved. OMRDD staff may conduct unannounced visits to any certified program at any time and will do so in response to complaints received from individuals with developmental disabilities,

family members, staff or members of the public.

**Training.** To keep providers current on quality assurance topics and thereby enhance the quality of services, OMRDD conducts biannual quality assurance provider training sessions. Routinely, 1,600 individuals representing 400 nonprofit providers attend these sessions. Topics covered include medical issues, fiscal audit issues, Life Safety Codes, incident management and current topics in the field of developmental disabilities. Most recent sessions have included presentations on how OMRDD reviews clinical, prevocational, and respite services.

**Using Information about Provider Performance.** The Statewide Standing Committee on Incident Review identifies trends and best practices in incident management, and communicates good safety practices information to nonprofit providers through safeguard alerts. The committee also sponsors training in incident management. The Early Alert Committee is an OMRDD Central Office group that monitors programmatic and financial information on the performance of nonprofit providers. The committee seeks to solve problems with the nonprofit providers involved before they escalate into situations that require drastic action. The committee has identified and provided technical assistance to successfully resolve several situations with the potential for negative outcomes. It also recommends policy changes with an impact on the provision of quality services.

**Limited Fiscal Reviews.** OMRDD now conducts limited fiscal reviews of nonprofit providers that include verification of: board of directors involvement, use of consumer personal allowance funds, financial viability, internal control systems, and the documentation of services claimed for reimbursement. Part of OMRDD's responsibility is to ensure that bills submitted by agencies for services rendered have verifiable, substantial docu-

mentation bases. Where there is insufficient documentation, OMRDD may take appropriate actions to ensure agencies' compliance.

Specific Comprehensive Five-Year Goals for Quality Assurance and Quality Improvement are found in Chapter 4.

### **Appropriate Service Settings**

At the end of the 1997-98 fiscal year, OMRDD's institutional population was 2,430, with 60 percent residing in developmental centers (DCs) and 40 percent in units offering specialized services. By the end of the 2004-05 fiscal year, those proportions changed dramatically: the funded institutional census was projected to be 1,696, with 30 percent in the DCs and 70 percent in specialized units. This shift is the result of two basic elements: the successful transition of most of the DC population to the community, and OMRDD's recognition of the need to provide specialized services to individuals with complex medical or behavioral needs in more structured settings until they can be appropriately served in the community. OMRDD continuously evaluates people in institutional settings for a return to the community.

Services for individuals with developmental disabilities who have intensive needs continue to be a priority for OMRDD. People with specialized or intensive needs who have mental retardation and developmental disabilities are best served in environments that can most appropriately meet their individual needs. OMRDD is able to offer services ranging from enhanced staffing for addressing behavioral needs to highly intensive services for individuals with extreme behavioral issues.

**Forensic Services.** Although they represent a small proportion of the total population served by OMRDD, people whose behavior presents a problem to their own health and safety and to the safety of the community require intensive services in

controlled settings. In order, from more to less restriction, the Centers for Intensive Treatment (CIT), Regional Intensive Treatment (RIT) Units, and Local Intensive Treatment (LIT) Units comprise a continuum of specialized secure environments that provide active treatment for persons with developmental disabilities who have offending, criminal or dangerous behaviors. Individuals can move from more to less restrictive settings as they progress in targeted areas. There are 606 funded opportunities for individuals who require these services.

**Multiply Disabled Units.** During the 2004-05 fiscal year, 374 residential opportunities are available in MDUs, which serve individuals who are dually diagnosed with developmental disabilities and psychiatric illnesses. Some of the current MDU residents originally lived in OMH facilities but transferred to the MDUs, where they are more appropriately served.

**Pre-Survey and Technical Assistance.** Maintaining quality services in institutional settings takes a multifaceted approach. An important component of this approach is the work done by OMRDD's Pre-Survey and Technical Assistance Team, which was established in 2001 to prepare for both recertification inspections by DOH and federal look-behind surveys by CMS. This team of experts reviews the developmental centers' practices in advance of DOH and federal inspectors, five to six months prior to the expiration date of the provider agreement. They assess compliance and work with the DDSO directors and their senior staff to correct any deficient practices.

Specific Comprehensive Five-Year Goals for Appropriate Service Settings are found in Chapter 4.

### **Managing the HCBS Waiver**

The primary vehicle in New York State for serving people with developmental disabilities is the HCBS Waiver. OMRDD, in collaboration with DOH, manages this

#### **Key Challenge: Coordinating the Use of the HCBS Waiver, NYS OPTS and Self- Determination to Achieve Individualized Services**

*While OMRDD's use of the HCBS Waiver has been unparalleled in its success, OMRDD has added other innovative service and funding mechanisms over the past two years that have given people with developmental disabilities even more choices. Through NYS OPTS, OMRDD is piloting a contract-based approach that will allow nonprofit providers to tailor services that precisely meet individual requests. In addition to NYS OPTS, the Self-Determination Pilot Project allows people with developmental disabilities to apply directly to OMRDD to design their own waiver service plan and use a budget developed just for them to procure approved staff, other supports, transportation and equipment. OMRDD's challenge in 2006-2010 will be to broaden the provider understanding of these new approaches so that they can effectively serve the individuals with developmental disabilities who are interested in utilizing them.*

### **Key Challenge: Accessible and Affordable Housing**

*Accessible and affordable housing is becoming increasingly difficult to obtain, especially in urban centers of New York State and particularly in New York City, Long Island and the suburban communities north of the City. While the high costs of housing are a challenge in all OMRDD residential programs, this is a special challenge for people with developmental disabilities pursuing arrangements for independent living. Efforts will need to be undertaken to help expand the availability of affordable housing for people with developmental disabilities who need it. All levels of government including local, state and federal housing authorities will need to work closely with nonprofit providers whose responsibilities include residential services, to maximize access to affordable housing programs and subsidies.*

federally funded Medicaid Waiver program for people with developmental disabilities. The Waiver began in 1991 serving fewer than 800 people. In 2004 enrollment exceeded 50,000 people.

**Growth.** Since its inception the HCBS Waiver has grown much more rapidly than long-established Medicaid programs, such as the ICF/DD and day treatment. HCBS Waiver costs are required to be equal to or less than the costs of ICF/DD programs. Growth has occurred through two avenues. First, as new people have been identified through the NYS-CARES initiative, the HCBS Waiver has been the primary funding source used to provide the scope of services sought by families and individuals with developmental disabilities. Second, converting existing programs that were fully state funded, such as sheltered workshops, supported employment and certain respite programs, to waiver funding have given thousands of individuals greater choice and service flexibility.

**Outside Assessment.** CMS is the agency within the federal Department of Health and Human Services that administers the Medicaid program. CMS conducted a six-month long program review and audit of OMRDD's HCBS Waiver during 2000. Their report praised New York for having "more than substantially met its obligations and assurances" to provide quality care. The report concluded that New York "achieved an admirable record of quality services," and that "the growth of the Waiver and the reduction of institutional placements is evidence of New York's success in developing a service system that supports people in the most integrated setting." New York also received praise for its spirit of cooperation, overall operations and superior performance in many areas. These included quality and oversight, opportunities for choice within an individualized service system, openness of communication with all constituents of the system, physical plants and fiscal efficiency. On

the basis of the positive outcome from the 2000 review, a second review was conducted by CMS in 2004. Again, the State's HCBS Waiver was found to be in substantial compliance and the waiver agreement was renewed through September 2009.

**Supporting Inclusion.** To encourage inclusion, OMRDD promotes the use of "natural supports" (unpaid help from family, friends and neighbors) and community resources under the HCBS Waiver. Expectations for the use of natural supports and community resources are stated in the policy manual *The Key to Individualized Services* for people in the HCBS Waiver. This policy is reinforced and monitored in a number of ways. First, the ISP form itself has a required category for natural supports and community resources. Second, the use of these types of supports is part of required ISP training for MSC service coordinators. Third, OMRDD follows up by randomly reviewing ISPs for quality improvement and compliance.

Specific Comprehensive Five-Year Goals for Managing the HCBS Waiver are found in Chapter 4

### **Improving the Process of Housing Development**

OMRDD continually refines the process, methods, and measurements used to assist nonprofit service providers in developing residential alternatives for individuals with developmental disabilities. Property cost thresholds established between OMRDD and the DOB are frequently reviewed against actual costs and real estate market trends, and are adjusted to reflect current conditions. This periodic update of the thresholds provides flexibility that is necessary to operate in the state's active real estate market.

The centralization of the Prior Property Approval (PPA) process that began in 1999 has provided for consistent and standardized reviews of capital proposals

and has resulted in maintaining and expanding the confidence of the finance community in the OMRDD service system. Under NYS OPTS, the procedure for developing housing has been enhanced through more timely and accurate reimbursement mechanisms and more streamlined review and approval, while maintaining the integrity of the PPA process.

In addition, procedures for determining fair market value have been refined to provide more useful and timely information to nonprofit providers acquiring housing by purchase or lease. Updated appraisal requirements reflect increased housing values in the downstate area, reducing paperwork and speeding turnaround time essential to successful acquisitions in active real estate markets.

Specific Comprehensive Five-Year Goals for Improving the Process of Housing Development are found in Chapter 4.

### **Improving Health Care Practices**

A core responsibility of the OMRDD system is to monitor and attend to the health of those who receive supports and services. The extent of this responsibility varies with the kind of services rendered. Those receiving residential services require effective systems in place to monitor health care and agencies must make adjustments to meet changes in the operation of the health care system.

#### **Status of Health Care Practices**

**Clinical Services Coordination.** Practices in monitoring clinical services are currently under review. A workgroup comprised of OMRDD staff, representatives from nonprofit providers, nonprofit provider associations and self-advocates has begun work on examining the role of clinical services coordination in certified residences. The workgroup may recommend the establishment of a clinical services coordination role, which should improve the quality of life for individuals with developmental disabilities by increasing the effectiveness of services and elim-

inating duplicate services.

**Clinics.** A substantial number of people with developmental disabilities need various kinds of therapy: physical, occupational, speech and others. These services often have been provided in clinics that are administered by DOH through Article 28 licensure or by OMRDD through Article 16 licensure. OMRDD is engaged in a thorough review of its regulatory, administrative and oversight practices in regard to Article 16 clinics. The goal is to ensure continued access to high-quality services that are fully integrated into the person's ISP and/or other program plans. In addition, DOH and OMRDD are engaged in ongoing discussions about the role that each agency plays in assuring access to medical, dental, and long-term therapies in the setting most appropriate to each individual's needs.

**Nursing Supervision.** State law requires adequate medical and nursing supervision of direct support staff who perform nursing functions. A milestone in complying with the law was achieved with the issuance of Administrative Directive 2003-01, which outlines the components of supervision required in residences operated or certified by OMRDD:

- A registered nurse must be available at all times to provide consultation and direction to direct support professional staff;
- Direct support professional staff must call the registered nurse before administering any new medication and whenever there is a change in the health status of the consumer; and
- Plans of nursing service must be developed for individuals with developmental disabilities who have certain medical conditions.

Meeting the requirements of the directive draws attention to nursing resources in the system. America is experiencing a critical shortage of nurses that affects all human service systems. Over the past few years,

### **Key Challenge: Facing America's Nursing Shortage**

*To a large extent, the system's difficulties in recruiting and retaining nurses will only be solved in the context of national and state efforts to combat the nursing shortage. According to the experts, necessary actions include making nursing a more attractive career choice, expanding nurse training programs, achieving higher graduation rates for schools of nursing, and bringing inactive nurses back into the workforce. Until the supply of nurses meets demand, OMRDD and nonprofit providers must be flexible and creative to meet their need for nurses in an extremely competitive situation. The OMRDD system will need to address, along with other systems, the issues of competitive nursing salaries and work to achieve a better quality of work life for nurses who serve in the system.*

OMRDD has launched an initiative to recruit new and retain existing nurses. New York State has instituted salary enhancements in areas of acute nursing shortages, specifically for nurses working with people with disabilities, making the developmental disabilities career ladder for nurses more competitive with hospital-based nursing opportunities. OMRDD is expanding its involvement with nursing schools and may offer OMRDD sites as clinical experience settings for nursing students. OMRDD is participating in a grant project to assist employees who wish to become nurses. OMRDD has developed a Nursing Action Plan to focus on promoting job satisfaction and enhancing the retention of experienced nurses. The Action Plan includes the establishment of a Commissioner's Advisory Committee on Nursing Issues with the participation of nurses from both the state and voluntary sectors.

In addition to work on ensuring an adequate number of nurses, OMRDD promotes technology that maximizes the efficiency of current system resources. The Nursing Action Plan includes steps to help in the retention of experienced nurses. These steps are: the development of an OMRDD-specific nursing information intranet page; the use of laptop computers for community-based nurses who work at multiple sites, and the use of enhanced electronic communication and documentation. Another technological solution is "telephone triage," in which nurses at call centers, using well-structured protocols, answer questions from on-site direct support professional staff. Using a grant from the State Department of Labor, OMRDD and the Rehabilitation Research and Training Institute conducted sessions around the state that trained more than 1,500 mental retardation nurses in telephone triage.

**Continuing Education.** Several OMRDD initiatives have improved the ability of staff in the system to deliver quality health care. In cooperation with DOH, OMRDD developed a session for regis-

tered nurses overseeing the care of individuals with developmental disabilities with diabetes, a complicated disease with constantly changing treatment options. OMRDD has joined with the Maimonides Society of Northeastern New York to sponsor bi-weekly educational programs for health care professionals that feature physicians and dentists from the Society presenting current information on many topics. These sessions use OMRDD's videoconferencing capacity to reach four remote locations.

**Oral Hygiene.** As the Willowbrook parties have pointed out, there is much work to do to bring quality oral hygiene to those served by OMRDD. The OMRDD Task Force on Special Dentistry, established in 2002, is a public-private sector partnership dedicated to excellence in oral health for individuals with mental retardation and developmental disabilities. The Task Force's 25 members represent New York's dental schools, hospitals, state facilities and other advocates. The Task Force has pursued its charge with enthusiasm and has been the driving force behind these positive initiatives. The Task Force has helped to:

- Replace outdated dental equipment with state-of-the-art equipment at dental clinics located at four DDSO campuses.
- Survey all Article 16 and 28 clinics offering dental services to establish the availability and location of services across the state. This information is now in a database and will eventually be made available to professionals and the public on OMRDD's website.
- Conduct a training session for Task Force members on oral sedation, which reduces reliance on hospital-based care.
- Purchase a video training program on oral hygiene for people with developmental disabilities with unlimited rights of reproduction. The video features Dr. Paul Glassman, the leading expert on

this topic in the country. The Task Force has conducted videoconferences for state and nonprofit provider staff on how to use the training video.

The Task Force is continuing its work. It will be seeking resources to undertake more ambitious initiatives.

**Infection Control.** Infection control is critical in facilities that serve persons with compromised immune systems. OMRDD, in cooperation with the Public Employees Federation, sponsored blood-borne pathogen training for DDSO infection control nurses. OMRDD, working with DOH, has developed procedures to assist nonprofit providers in responding to outbreaks of infectious diseases in residences and day programs. HIV/AIDS prevention is important for people with developmental disabilities as well as for the general population. OMRDD is an active member of the multiagency HIV Prevention Planning Group. OMRDD, the AIDS Institute and Special Olympics have incorporated HIV education into the Healthy Athlete Program of the Special Olympics. Protecting the health of staff as well as individuals with developmental disabilities is vital in the OMRDD system. One measure OMRDD takes is to participate in the Needlestick Prevention Task Force, which works to reduce the risk of blood-borne pathogen transmission via needle stick and lancet injuries.

**Health and Nutrition.** "Be Healthy...Be Happy: A Health and Nutrition Education Program" is a collaborative project of OMRDD and United Cerebral Palsy of New York City. This health and nutrition program provides education for individuals with cerebral palsy and intellectual disabilities, a group that is at high risk for health problems. The goals are to:

- Improve the health and nutritional practices of 64 individuals in the first year and 96 more in the second year;
- Train agency support staff in health promotion awareness and follow through;

- Establish an empirically-based curriculum for use statewide; and
- Train agency instructors in use of the curriculum.

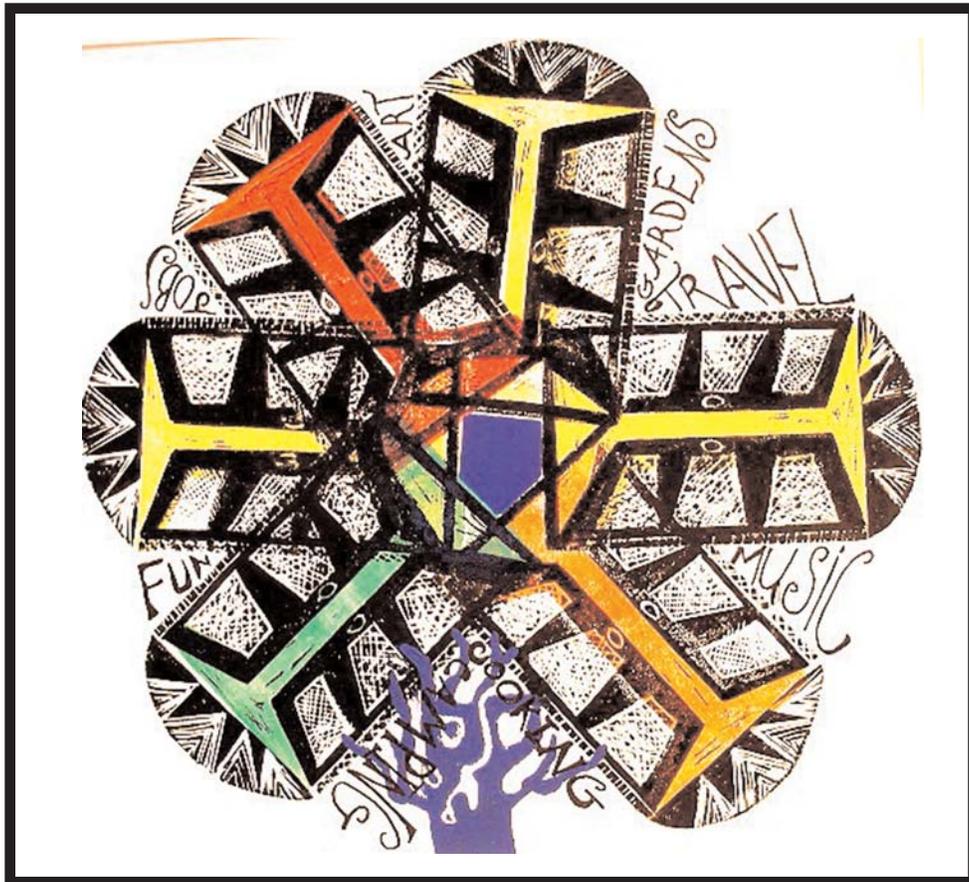
Each participant selects personal health goals that are incorporated into the ISP and each is assigned a classroom mentor who facilitates the adoption of healthy lifestyle activities. Following the first 14-week session the 32 participants understood more about healthy choices and had significantly improved their overall total health. A second session is now being completed. OMRDD promotes better nutrition for the people with developmental disabilities it serves by working with state and nonprofit providers to improve menu planning and encouraging healthy food choices.

**Medicaid Managed Care.** In 1997 New York State implemented a mandatory Medicaid managed care program. OMRDD and nonprofit providers worked to ensure that most people with developmental disabilities served by OMRDD will always have a choice of whether or not to join a Medicaid managed care plan and that OMRDD long-term care services will continue to be provided outside of managed care. However, persons in OMRDD District 98 (a special statewide district for certain groups of OMRDD individuals with developmental disabilities that is separate from county social services districts) do not have an opportunity to choose a managed care plan. OMRDD worked collaboratively with DOH and Albany County officials to develop a pilot program that would allow persons with developmental disabilities living in Albany County who are in OMRDD District 98 to choose to enroll in a managed care plan. Several individuals with developmental disabilities in Albany County are currently evaluating the managed care option that they have as a result of this pilot project.

Specific Comprehensive Five-Year Goals for Improving Health Care Practices are found in Chapter 4.



# Vision and Goals



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## IV. Vision and Goals

As OMRDD moves into the future it remains guided by its Mission Statement and its Guiding Principles, found in Chapter 1 of this Plan. The vision for the next five years will be to meet the demands for quality, increased choice and more individualized services. This brief conclusion seeks to clarify how this vision will be implemented through the pursuit of the major planned agency initiatives. The Plan ends with a list of specific goals for each of the areas discussed in Chapter 3.

### Major Initiatives for the 2006-2010 Plan Period

In embarking upon the key actions outlined in this comprehensive Five-Year Plan for 2006-2010, OMRDD will remain true to its mission and governing principles. These initiatives will help realize a support system for people with developmental disabilities and their families that implements the vision for higher quality and more individualized services and supports.

**NYS OPTS.** The development, testing and expansion of the NYS OPTS program is a high priority. This program allows those receiving services to participate in the design of services that will target their specific needs. Individuals with developmental disabilities and families will drive the services that are developed under NYS OPTS. NYS OPTS will promote inclusion and personal choice, and offer flexibility and opportunity for efficient and effective use of the resources available. All participants in the system will benefit from the increased flexibility. Those who receive services are more likely to get truly individualized services and the efficiencies will free up resources to serve more people. Under NYS OPTS, OMRDD will be the provider of record and will subcontract the provision of serv-

ices to the nonprofit provider. It is anticipated that the individuals and their families seeking services will almost always participate in and frequently lead in setting the terms in the NYS OPTS agreement between OMRDD and the nonprofit provider. The agreement will detail expectations for the program, including those advanced by individuals with developmental disabilities and their families. Individuals with developmental disabilities who are receiving services, their parents and other family members, advocates, nonprofit providers and nonprofit provider associations, local government state staff and other interested representatives will continue to collaborate with OMRDD in implementing and evaluating the program.

**NYS-CARES II.** OMRDD will work to effectively administer NYS-CARES II, which is critical to carrying forward the success of the original NYS-CARES initiative in providing out-of-home residential services to those who need them. OMRDD will refine and confirm service planning information about those who seek NYS-CARES services, increase the scope of practical choice that individuals with developmental disabilities have in residential services by creating a database that lists the characteristics of all residences, and measure customer satisfaction with services in order to increase satisfaction.

**Participation and Collaboration.** Over the past few years OMRDD has improved what was already a strong value in the system: participation of system constituents, and especially parents, advocates, and individuals with developmental disabilities, in planning for and providing services. OMRDD will continue to build on this tradition and seek new ways of maximizing the benefits of participation. Examples of this are the partnerships OMRDD has forged with SANYS and Parent-to-Parent. OMRDD and SANYS have also partnered in an initiative to bring person centered planning to individuals with developmental disabilities who live in

large ICFs/DD, exploring with the residents options for more integrated community residential settings.

**Individualized Supports and Services.** OMRDD will continue to make supports and services more individualized. An example of this is the work that OMRDD and a committed group of individuals with developmental disabilities and families have engaged in to make self-determination a reality by using the new CSS feature of the HCBS Waiver. CSS allows for more individualization of services through customer control of the supports and services budget. Along with enabling individuals with developmental disabilities to build the lives they want, implementing self-determination will challenge rigid system procedures within the nonprofit and the state provider structures, thereby forcing more flexibility. OMRDD will also continue to work to improve person centered planning, work opportunities, transportation options and services for persons with developmental disabilities who have specialized needs.

**Workforce.** Quality services depend greatly upon a stable, motivated and well-trained direct support professional workforce. OMRDD will continue to advocate and work for more competitive wages for its direct support professional workforce. Along with higher wages, creating a stronger career structure for direct support professionals would help retention. OMRDD will promote steps that strengthen the career structure, such as increased training and education and credentials linked to education and service. A key factor in turnover, well known from research, is the quality of supervision at the work site. OMRDD will continue to promote quality management practices throughout the system, by providing and encouraging training for boards of directors of nonprofit providers, managers, supervisors and direct support professionals.

## Comprehensive Five-Year Plan Goals

The following is a listing of specific goals related to each issue area that OMRDD will pursue over the five-year Plan period. These statements of projected actions are related to the issues found in Chapters 2 and 3. References to these discussions in the body of the Plan are provided for each area under the title.

### NYS-CARES II

*Discussion of this issue is found on p.30*

#### Goals:

- Evaluate and adjust NYS-CARES II to continue to meet the future demand for residential services for people in the community.
- Continue to develop individualized housing options for persons using NYS-CARES II.

### NYS OPTS

*Discussion of this issue is found on p.30*

#### Goals:

- Develop the capacity to provide enhanced individualized services for a variety of special populations, such as the frail elderly, those with a dual diagnosis, persons with autism and children.
- Increase emphasis on models of service that support portability of resources.
- Provide the mechanism to right-size day and residential programs.
- Evaluate NYS OPTS projects on an ongoing basis to assure continued adherence to the guiding principles.
- Develop an internet-based and secure recording system for NYS OPTS services to enable faster payments to providers.
- Develop and implement a customer satisfaction survey for NYS OPTS in partnership with providers, self-advocates and family members.

## Self-Determination and Self-Advocacy

*Discussion of this issue is found on p.24 and on p.33*

### Goals:

- Work with various control agencies in an effort to streamline the process for applying for self-directed supports funded through the HCBS Waiver.
- Increase access to service coordination and other supports necessary for self-determination.
- Expand provider participation in self-determination and self-advocacy through training.
- Support programs to introduce self-advocacy to young adults with developmental disabilities.

## Quality Staffing

*Discussion of this issue is found on p.24 and on p.34*

### Goals:

- Continue the OMRDD focus on the competitiveness of direct support professional salaries.
- Provide oversight and evaluation of the impact of salary increases on direct support professionals.
- Increase training for habilitation staff to increase stability.
- Promote training for site managers and mid-managers in voluntary agencies.
- Establish the Direct Support Professional Advisory Committee to institute positive changes for direct support professionals.
- Assess the effectiveness of OMRDD's web-based recruitment tools and make improvements as indicated over time.
- Continue to collaborate with provider associations to improve retention of direct support professionals.

## Collaboration Among Governmental Agencies

*Discussion of this issue is found on p.24 and on p.38*

### Goals:

- Collaborate with the SED to identify best practices in transition planning and disseminate them to others.
- Identify and disseminate best practices developed through NYS OPTS for services jointly planned and funded by state agencies, including OMRDD, OMH, OASAS, and SOFA, to DDSOs, providers and counties.
- Increase employment-related opportunities through collaborative pilot projects with other state agencies and localities.

## Special Populations

*Discussion of this issue is found on p.25 and on p.39*

### Goals:

- Explore opportunities for cross-system collaboration (OMRDD, SOFA, OMH, and DOH) in community-based residential and day program development for individuals who are aging.
- Address issues around community-based supports for people with developmental disabilities who are medically frail.
- Explore developing specialized residential, day, transitional and other services for people with Autism Spectrum Disorders through increased collaboration and training among providers serving people with autism.
- Develop specialized residences for persons with intensive behavioral needs currently living in institutional settings.

- Explore family care with built-in clinical supports as an option to expand residential opportunities for young adults.
- Continue to enhance cultural competency among providers and the workforce.
- Further expand the types of services provided by multicultural providers.
- Continue OMRDD technical support to multicultural providers through trainings on specific topics, such as management techniques, fiscal reporting requirements, board responsibilities, program development, internal controls, and programmatic best practices.
- Develop a mentorship capacity for multicultural providers to assist newly emerging multicultural providers during the start-up years.

### **Person Centered Planning and Participation in Planning**

*Discussion of this issue is found on p.26 and on p.42*

#### **Goals:**

- Work with nonprofit providers to increase understanding of the value of person centered planning through training and other incentives.
- Promote organizational change fostering person centered services.

### **Transportation**

*Discussion of this issue is found on p.26 and on p.43*

#### **Goals:**

- Explore transportation issues and make recommendations for system improvements.
- Advocate for collaborative solutions to transportation problems confronting people with developmental disabilities, especially as related to paratransit scheduling.
- Promote innovative transportation projects, possibly through NYS OPTS.

- Consider waiver-supported approaches to transportation to enhance supports for people so they can more easily work and volunteer in the community.

### **Access to Information**

*Discussion of this issue is found on p.26 and on p.44*

#### **Goals:**

- Continue to improve the OMRDD website, adding a search function.
- Increase the dissemination of information about OMRDD supports and services by collaborating with the medical, educational, social services and human services communities.

### **Community Inclusion and Community Building**

*Discussion of this issue is found on p.26 and on p.45*

#### **Goals:**

- Increase public involvement and participation in the lives of people with developmental disabilities through citizen advocacy initiatives.
- Continue to consult with self-advocates to build upon the platform of inclusion in communities throughout NYS.
- Explore best practices and their relationship to risk management with the aim of identifying those that promote individualized services.

### **Work and Employment**

*Discussion of this issue is found on p.26 and on p.46*

#### **Goals:**

- Create an environment to promote individualization of day services for people who choose these services.
- Build better working relationships with local school districts to assure effective transition planning into employment opportunities.

- Continue to expand employment opportunities, possibly through NYS OPTS.
- Disseminate employment best practices among agencies.
- Explore the expansion of employment opportunities within the public and human service systems for people with developmental disabilities.

### **Family Support Services**

*Discussion of this issue is found on p.47*

#### **Goals:**

- Continue to support families through the provision of services that are flexible, creative, and innovative.
- Provide services to families that are specific to their needs in maintaining family unity and a high quality of life.
- Support families to stay together.

### **Quality Assurance and Quality Improvement**

*Discussion of this issue is found on p.47*

#### **Goals:**

- Utilize the COMPASS programs and the emphasis on excellence as a means of promoting high-quality, person centered supports and services.
- Continue efforts to obtain and effectively use customer satisfaction data in assessing quality.
- Promote a variety of system-wide continuous quality improvement initiatives.

### **Appropriate Service Settings**

*Discussion of this issue is found on p.49*

#### **Goals:**

- Continue to gradually downsize New York State's general developmental center population as appropriate to the needs of those

being served.

- Develop community-based living arrangements for people who require specialized supports.

### **Managing the HCBS Waiver**

*Discussion of this issue is found on p.49*

#### **Goals:**

- Continue to investigate opportunities for more flexible use of the HCBS Waiver.
- Continue to encourage enrollment in the HCBS Waiver to assure person centered and individualized services are afforded to people with developmental disabilities.
- Improve the quality of waiver services through staff training, self-assessment exercises and encouraging innovative service proposals.
- Support self-directed service models that can be developed through the HCBS Waiver.

### **Improving the Process of Housing Development**

*Discussion of this issue is found on p.50*

#### **Goals:**

- Work with control agencies and other state agencies to refine administrative processes to enable property acquisition in active real estate markets in a timely and effective manner.
- Continue the development of residential opportunities for smaller groups of people.
- Continue to promote individual preferences by offering a variety of housing options.
- Educate families and individuals about the range of available housing opportunities throughout the OMRDD system.

## **Improving Health Care Practices**

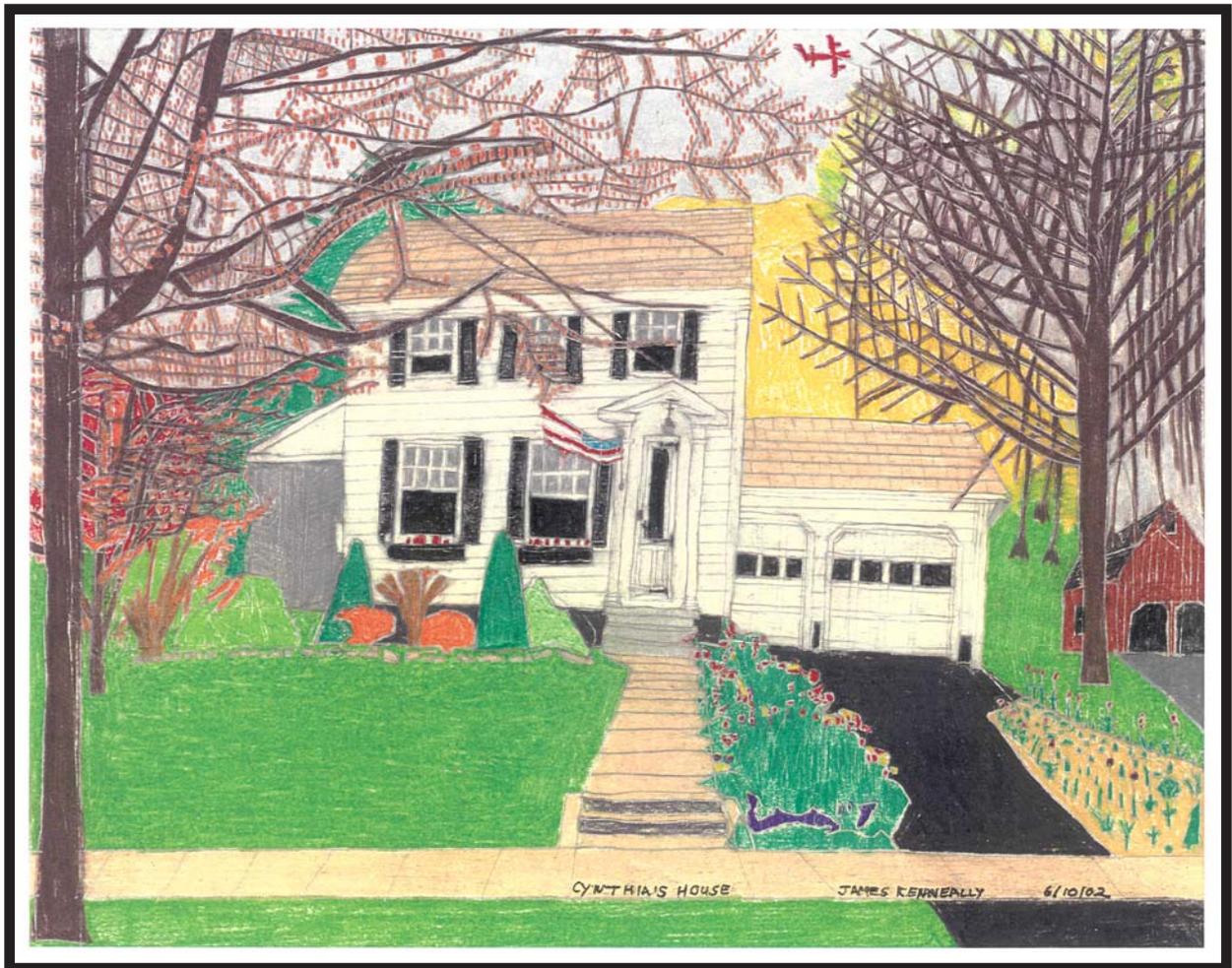
*Discussion of this issue is found on p.51*

### **Goals:**

- Continue to improve clinic services so that people have access to the services they need through a coordinated and efficient system of care.
- Explore new models for delivering and coordinating necessary long-term clinical supports.
- Explore new technology and best practices in nursing to maximize the effectiveness of OMRDD's nursing resources.
- Explore new initiatives aimed at promoting wellness and disease prevention.
- Promote the Dental Task Force and explore the possibility of extending this model to other areas of health care.



# Appendix A: Public Hearing Summary



"Cynthia's House"  
by James Kenneally  
2002 - Colored Art Pencils

# Appendix A: Public Hearing Summary

As an important step in gathering public input to the new plan, and consistent with Section 5.07(b)(2) of Title A, Article 5 of the New York State Mental Hygiene Law, eight regional public hearings were held in February and March of 2005. At these hearings, Commissioner Thomas Maul and others received public testimony on a draft of this Plan. The draft Plan was distributed during January 2005 for public review prior to the hearings. Copies were also available at the hearings.

The public was invited to attend the hearings to learn more about the Plan and to offer comment. In addition, people with an interest in key issues facing the field of developmental disabilities and the goals proposed in the Plan were encouraged to give testimony.

People who wished to offer testimony were asked to notify local OMRDD staff and reserve a time to speak. Speakers were requested to limit oral comment to five minutes and to submit three written copies of testimony at the hearing. Comment was also submitted by mail to the OMRDD Bureau of Planning and Service Design. People who required sign language interpretation, or other special accommodation to attend a hearing, were asked to inform local contacts in advance so that appropriate arrangements could be made.

Public hearings for the Plan were held at:

## Long Island

Sheraton Long Island, Smithtown  
2/9/2005 4:00 p.m.-7:00 p.m.

## Capital District

Prospect Child & Family Center,  
Aviation Rd., Queensbury  
2/14/2005 10:00 a.m.-2:00 p.m.

## Western

Southeast Works, Lincoln St., Depew  
2/15/2005 4:00 p.m.-7:00 p.m.

## Central NY

Central NY DDSO, S. Wilbur Ave.,  
Syracuse  
2/16/2005 11:00 a.m.-3:00 p.m.

## Broome

Binghamton Regency, One Sarbro  
Square, Binghamton  
2/17/2005 10:00 a.m.-2:00 p.m.

## New York City

NYCRO, 75 Morton St., Manhattan  
3/3/2005 10:00 a.m.-2:00 p.m.

## New York City

NYCRO, 75 Morton St., Manhattan  
3/3/2005 6:00 p.m.-8:00 p.m.

## Taconic

Central Hudson Gas & Electric, Rte. 28,  
Kingston  
3/7/2005 11:00 a.m.-3:00 p.m.

## Hearing Participants

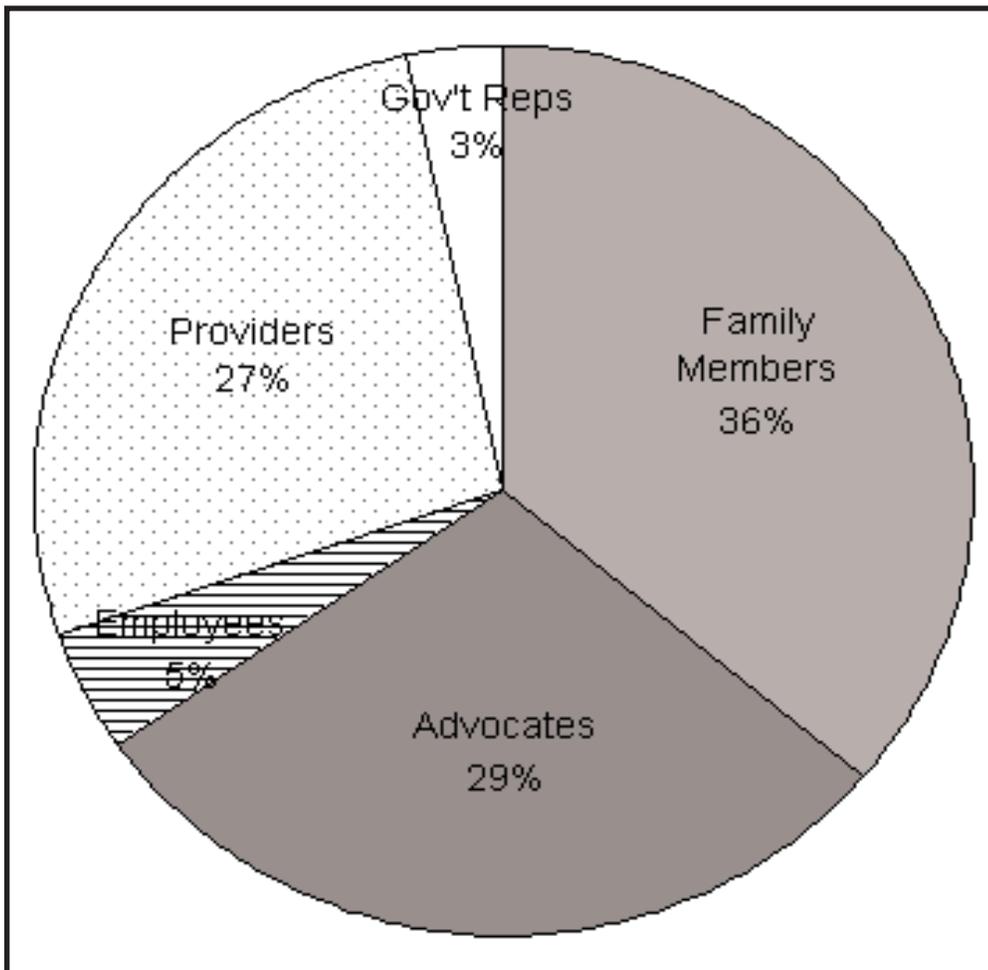
A total of 165 people presented testimony at the hearings and ten submitted testimony to OMRDD Central Office. Nearly two-thirds of all speakers were either parents or advocates.

Total Number of Participants Who Presented Testimony: 165

Total Number of Participants Who Submitted Written Testimony: 10

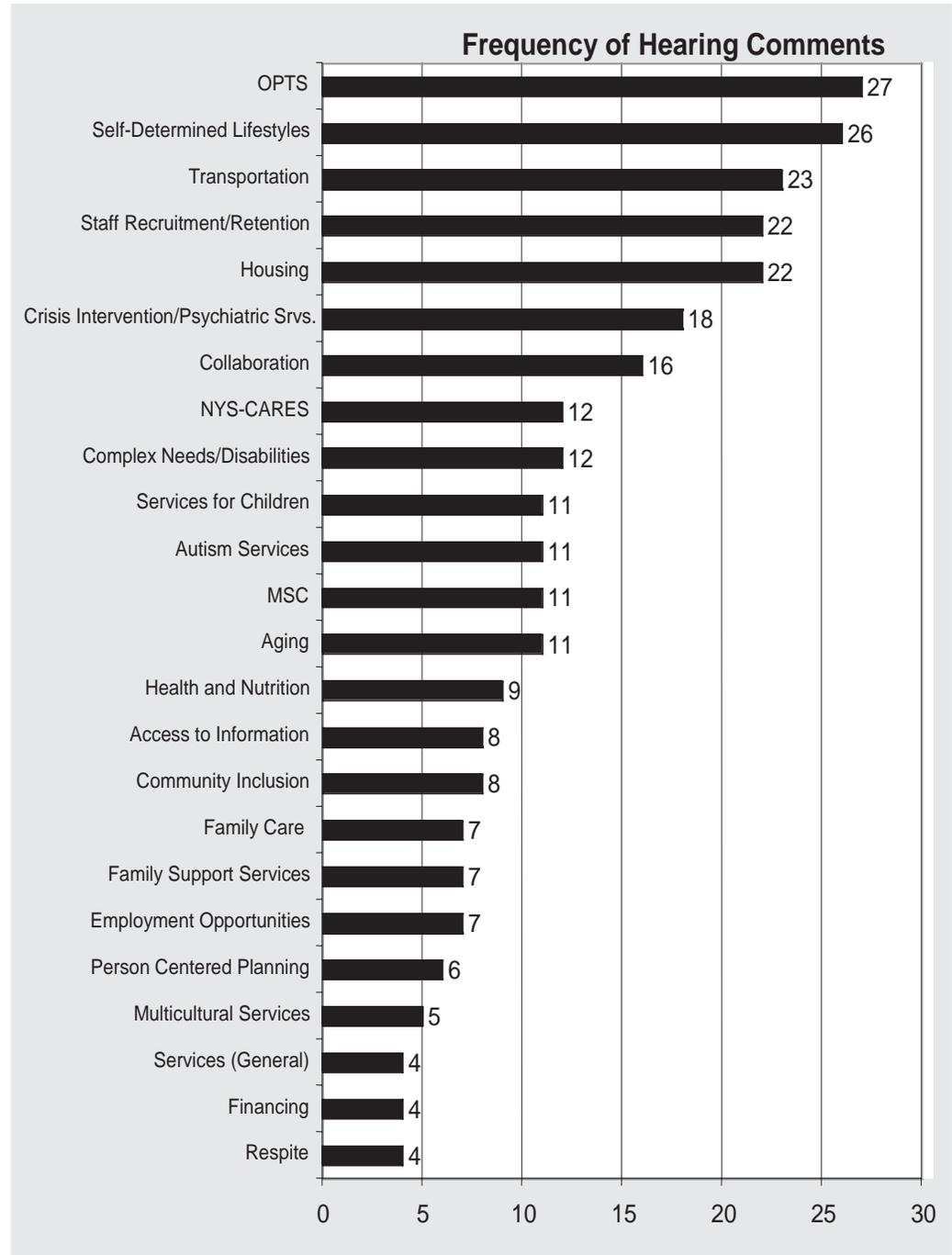
	#	%
<b>Family Members</b>	<b>63</b>	<b>36.0%</b>
<b>Advocates</b>	<b>51</b>	<b>29.1%</b>
<b>Employees of Public/Private Agencies</b>	<b>8</b>	<b>4.6%</b>
<b>Providers</b>	<b>47</b>	<b>26.9%</b>
<b>Government Representatives</b>	<b>6</b>	<b>3.43%</b>
	<b>175</b>	

### People Who Testified at 5.07 Plan Hearings



## Content of Testimony

The table below shows the topics that were mentioned most at the hearings.



The individuals testifying included 51 self-advocates, 63 family members, 47 providers, 8 staff members, and 6 government representatives. The following is a summary of the relevant issues covered:

## **OPTS**

Participants praised New York State Options for People Through Services (NYS OPTS) was a good extension of the Office of Mental Retardation and Developmental Disabilities' (OMRDD) commitment to person centered planning and would allow agencies to find creative solutions. However, some speakers felt that the process of developing an OPTS contract takes too long and is bureaucratic. It was suggested that OMRDD prioritize proposals so that those addressing high priority needs take precedence over other proposals. Also, some believed there must be collaboration with other state agencies, counties and federal entities for OPTS to be most effective.

## **Self-Determined Life Styles**

Many self-advocates talked about how self-advocacy and self-determination have changed their lives for the better. Those receiving services through Consolidated Supports and Services (CSS) were very happy with the self-determination pilot project and wanted CSS to be expanded. However, some thought there was too much red tape and that there was misunderstanding about CSS and the pilot project. Speakers wanted it made clear that self-determination is for everyone, even those with complex medical needs, autism, and other severe disabilities. It was suggested that OMRDD reach out to recent high school graduates and their families to encourage participation. Speakers also wanted the speaker's bureau to be supported and expanded. In addition, some testified that people with developmental disabilities need education on how to be self-advocates since it is their voices, individually and collectively, that break down barriers and build community bridges.

## **Transportation**

Many individuals expressed frustration that the unavailability of transportation options prevents individuals from fully participating in their communities. Some stated that agencies need more vans, including rear-loading vans for wheelchairs, so that people can participate in community activities in smaller groups and individually. Some expressed concern about the length of time people with developmental disabilities spend traveling to and from day services. Participants suggested that perhaps individuals can own "shares" in a vehicle (like a co-op) or use taxi-type services to give them more access. Others suggested promoting innovative projects through NYS OPTS, seeking federal funding options, considering waiver-supported approaches, working to ensure that public transportation is more accessible, and creating increased competition and choice in the selection of carriers.

## **Staff Recruitment & Retention**

Participants appreciated OMRDD's continued commitment to raise base salaries for direct support professionals and OMRDD's focus on improving working environments through greater resources, training and the creation of career ladders. However, some expressed concern that agencies still have difficulty retaining quality direct support professionals and service coordinators, and that this impacts on the quality of care provided. Commenters suggested that OMRDD develop creative approaches to redeployment of staff; for example, sharing personnel across programs, pooling of staff among agencies, and outsourcing to personnel agencies. It was also suggested that OMRDD look at multiple approaches to attracting and retaining workers, such as tuition reimbursement, increased benefits, and marketing tactics.

## **Housing**

Speakers appreciated that the Plan placed priority on streamlining residential development approval procedures so that

providers could participate in active real estate markets. But speakers still believed that the property acquisition process takes too long, that OMRDD's capital thresholds are too low, and that finding affordable housing remains a major concern. Others stressed the importance of downsizing the larger IRAs and continuing to move individuals from the Developmental Centers. Speakers suggested that OMRDD establish an information database to help people with developmental disabilities and their families navigate the home acquisition process. Some also suggested that OMRDD encourage the development of small agencies or agency units whose purpose is to help find and arrange self-directed housing and services. In addition, speakers recommended that OMRDD collaborate with housing agencies to develop generic mid-to-low income housing.

### **Crisis Intervention/Psychiatric Services**

Speakers felt that more resources are needed to serve people with dual diagnoses and behavioral issues. They wanted more collaboration among the Office of Mental Health (OMH) and local mental health departments. Several expressed concern that some individuals were spending too much time in hospital beds, when, with the appropriate supports, they could be supported in the community. Speakers wanted more short-term crisis services, psychological services, and clear guidelines on how to serve people with behavioral issues in the community. A participant requested that OMRDD develop individualized services for people with intensive behavioral needs rather than "specialized residences," since these individuals must learn to socialize and communicate appropriately in the community.

### **Collaboration**

Speakers expressed appreciation to OMRDD for closely collaborating with providers, families, and people with developmental disabilities. They also liked that

the Plan addressed the need for OMRDD services to be coordinated with other agencies. Many felt strongly that in order for individuals to receive the most effective services, there must be more collaboration with early childhood providers, schools, State Education Department (SED), OMH, local counties, Vocational and Educational Services for Individuals with Disabilities (VESID), Department of Labor (DOL), Department of Health (DOH), Office of Alcohol and Substance Abuse Services (OASAS), State Office for the Aging (SOFA), local housing and federal agencies. Many believed that screening, eligibility criteria, and service planning should look at the complete person, at all of a person's needs. A commenter suggested that various agencies contribute to a central funding source which would supplement funding for people with multiple needs and be administered with a person centered planning philosophy. Some felt that OMRDD could do more to include county government in determining priorities and policies and in the sharing of information. A commenter applauded the consortia of providers working under a DDPC grant to foster training, curriculum development, planning and positive communication between OMRDD and OMH, and requested that OMRDD continue to support the work of the consortia after the grant ends.

### **NYS-CARES**

Speakers lauded the NYS-CARES program and said it had addressed much of the existing housing need. Speakers were grateful that NYS-CARES II would continue to ensure that persons with developmental disabilities and their families have access to out-of-home residential services.

### **Individuals with Complex Health Care Needs/Significant Disabilities**

Parents were concerned about finding an appropriate placement for their children who are medically frail when they age out of school. Speakers also felt that the Plan didn't adequately address the needs and

concerns of individuals who are severely and profoundly disabled. Individuals with developmental disabilities and their families need additional supports and services to help them cope with complex disabilities. Some participants felt that OMRDD should make a special effort to ensure that all individuals, even those with complex health care needs, have access to individualized services.

### **Services for Children**

Participants appreciated that the Plan addressed non-school needs of young children. Speakers wanted more collaboration with schools to ensure continuity of services. Also, speakers felt there should be additional funding for respite, residential habilitation services, after school, and summer programs. Others expressed concern that bureaucracy prevented children from getting services in a timely manner. Testimony was provided on needs for more housing options for children who are medically fragile and for those with dual diagnoses. Speakers also indicated a concern that more staff should be trained in functional behavior analysis.

### **Autism Services**

Speakers stated that because the prevalence of autism has increased, there should be a commensurate increase in funding. Some felt that the Plan should do more to address the need for therapeutic services, including occupational, physical, speech, developmental, and behavioral therapies. Some believed that families need additional services, including counseling, crisis-intervention and respite. Speakers were also concerned about the difficulty of finding day programs and transitional services. In addition, some believed that staff need to be better trained to work with people with Autism Spectrum Disorders.

### **Medicaid Service Coordination (MSC)**

Speakers commended MSC as a great service to individuals and families. However, some were concerned with the large caseloads and the amount of paperwork. Others expressed concern that when service coordinators work for the same agency that provides services to an individual, a conflict of interest exists that may be detrimental to the individual. Some felt that service coordinators need to be more knowledgeable of available service options and that service coordinators need more training to ensure that individuals with developmental disabilities are true participants in the planning process. One speaker mentioned that for people with developmental disabilities living at home, MSC can appear to be intrusive, controlling, and inflexible.

### **Aging Services**

Speakers were encouraged that the Plan targeted services for the aging. One commenter stated that there should be a spectrum of care for the elderly that addresses special needs at the onset of the aging process through end-of-life care. This would require a blending of funding sources from multiple agencies. Speakers felt that older adults should be able to age in place with needed environmental and staffing modifications. They also felt that the elderly should be able to decide whether or not they want to attend a day program.

### **Health/Nutrition Issues**

Speakers advocated for the creation of training programs that help individuals with developmental disabilities learn how to manage their own health care and encourage healthy lifestyle choices. Some testified that there should be greater focus on ensuring that individuals with developmental disabilities have the same access to quality medical and dental care as "typical individuals." Participants mentioned the continuing nursing shortage and suggested that OMRDD form a nursing task

force to develop a plan to attract nursing professionals to work with individuals with developmental disabilities as an alternative to positions in traditional health care settings. Some stated that doctors and clinical staff need more personal skills training so that they treat all people under their care with respect and dignity. One participant stated that OMRDD should consider redesigning its clinical service system to reflect current individual needs, provider management models, and current fiscal realities.

### **Access to Information**

Speakers stressed the importance of getting information on service options and service availability to self-advocates, advocates, family members, and provider staff. Some stated that more families need to be informed about the opportunities presented through NYS-CARES II and NYS OPTS. Some suggested encouraging grassroots outreach, enhancing OMRDD's website, and creating information centers at each DDSO.

### **Community Inclusion**

Speakers were very supportive of OMRDD's commitment to community inclusion, but felt more needs to be done. Some believed that more staff and vehicles are necessary to facilitate community integration. There were concerns that while more and more individuals are moving into the community, some are not truly becoming integrated and not fully participating in their communities. One commenter suggested that OMRDD explore the Visitability initiative; this is a housing design approach whose purpose is to integrate basic accessibility features into all newly built homes, thus allowing people in wheelchairs to easily visit others in the community. Many felt that OMRDD should help educate the public so that people without disabilities are more accepting and welcoming of those with disabilities.

### **Family Care Services**

Participants felt that the Family Care program is an excellent one that should be expanded. Several people advocated for making family care a higher priority at OMRDD. Some felt that specific Family Care rules and regulations detract from the sense of family. Others felt that OMRDD must plan for the care of individuals living with aging family care providers. Others stated that family care providers need access to health insurance, disability insurance, retirement benefits, and more respite.

### **Family Support Services**

Speakers appreciated that Family Support Services (FSS) continue to play an important role at OMRDD. However, some thought that these services should have been emphasized more in the Plan and in OMRDD's budget. Speakers also requested more after school and recreation programs, as well as transportation to these programs. Some worried that as specific FSS shift to waiver services, parents will have fewer opportunities to influence their design.

### **Employment Opportunities**

Participants felt there need to be more employment opportunities, as well as more training to prepare individuals for jobs. Commenters wanted consumers to be better prepared to work with the "non-disabled." It was felt that only with the appropriate social, financial, and travel skills will people with developmental disabilities be able to cope with full-time employment.

### **Multicultural Services**

Changes in the cultural and ethnic demographics of New York City were described. Participants noted that, according to the Year 2000 census, 65 percent of the New York City population is now considered multicultural. Given the increasing multicultural diversity of New York City, concern was expressed that this plan did not adequately address a perceived

need to increase the management capacity of minority providers and to stimulate minority-operated programs and initiatives. These issues were considered to have been more completely addressed on prior OMRDD Five Year Plans, specifically 1990-1995. Specific recommendations were provided: support for agency start-up; funding carve-outs; access to on-site technical assistance; mentorship funding for existing multicultural agencies; and support for establishment of a Multicultural Provider Association. Testimony was also provided on the need to increase access to linguistically competent and culturally sensitive staff and services, and to ensure access to culturally sensitive personal care products, ethnic foods, and religious/spiritual activities and services.

### **Person Centered Planning**

Self-advocates were happy with person centered planning and believed it had helped enrich their lives. A commenter hoped that OMRDD would continue to encourage person centered planning philosophies and processes, and encourage staff at all levels to understand and embrace them. Some speakers felt that often staff failed to review the individuals' person centered plans and as a result, individuals still received generic services. Participants wanted all individuals with developmental disabilities to have access to person centered planning.

### **Services (general)**

Speakers believed the goal of encouraging enrollment in the Home and Community Based Services (HCBS) Waiver is commendable; however one commenter stated that at times, families have difficulty getting services until a crisis occurs. A speaker felt that while the Plan addressed the expansion of current services, it didn't address improving these services. With the creation of OPTS, some were concerned that regular waiver services would not receive the same support. Some felt that services are still not individualized

enough. Others felt that OMRDD should further refine and develop its capacity to maintain accurate waitlists for services.

### **Financial Support**

Speakers felt that OMRDD needs to continue to support the portability of funding, that is, ensure that funding is linked to the person and not to the agency. Some who testified were concerned about the possibility of government cuts to Medicare and Medicaid and wanted OMRDD to factor this possibility into its long-term plans. A commenter stated that, at times, OMRDD does not support program models that are no longer favored by OMRDD and this isn't always beneficial to people with disabilities. Others expressed concern that the service system is not adequately funded for individuals with special needs. Speakers felt that additional funding is not always available when individuals' needs change and for individuals who need full-time supports and assistance to live independent lives.

### **Respite**

Participants stated that it was difficult to find respite, especially for individuals who are medically frail.