



NYS Office of Mental Retardation & Developmental Disabilities

Putting People First

Office of
Mental Retardation and
Developmental Disabilities

Statewide Comprehensive Plan 2008-2012

We help people with developmental disabilities live richer lives.



New York State
David A. Paterson
Governor

**Office of
Mental Retardation
and Developmental Disabilities**
Diana Jones Ritter
Commissioner

October 1, 2008



Dear Friends and Colleagues,

I am pleased to be able to present to you the Five Year Plan: 2008-2012 for the New York State Office of Mental Retardation and Developmental Disabilities.

As promised in my letter to you accompanying last year's Plan, the present document reflects a year's worth of reflection and hard work by all system stakeholders to revisit, clarify, and strengthen OMRDD's strategic vision and mission. As a result of that important process, OMRDD has adopted its new mission statement, "We help people with developmental disabilities live richer lives." Our collective vision has a singular focus: to assist the people we serve to enjoy meaningful relationships, experience health and growth, live in the home of their choice, and fully participate in their communities. The Plan chapters are organized around these essential quality of life outcomes, and they describe a multitude of initiatives, programs, and activities aimed at improving the service system's capacity to deliver on this promise.

This year marks OMRDD's 30th anniversary, and we should celebrate our collective success in building an exemplary community-based system of services and supports. Many feel we are on the brink of a shift in the way services should be designed and delivered. People with developmental disabilities have made it clear that they want "a life" not "a program," and there is consensus that in order to achieve this, we must increase access to more customized, person centered, and personally controlled services. High on OMRDD's agenda is to continue to work with self-advocates, families, and providers to lead that shift in a way that is both "customer driven" and fiscally prudent.

As part of the commitment to improving our ability to deliver the types of supports people and families want, we are instituting an aggressive program of performance measurement at OMRDD. You will see performance indicators throughout the Plan and we intend to be accountable to them.

I want to take this opportunity to thank the hundreds of people who came to the OMRDD forums over the summer, and to the public hearing in September, to offer testimony on the Plan. We listened and incorporated your ideas and insights. I also want to thank all those who contributed to creating the Plan, and to the thousands of people who work every day to provide service, leadership, and advocacy. Through your efforts, I am confident we will continue to build a better service system and a more inclusive society.

Sincerely,

A handwritten signature in black ink, appearing to read "D. Ritter". The signature is fluid and cursive.

Diana Jones Ritter
Commissioner



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Chapter 1: Introduction

The Evolution of a Service System

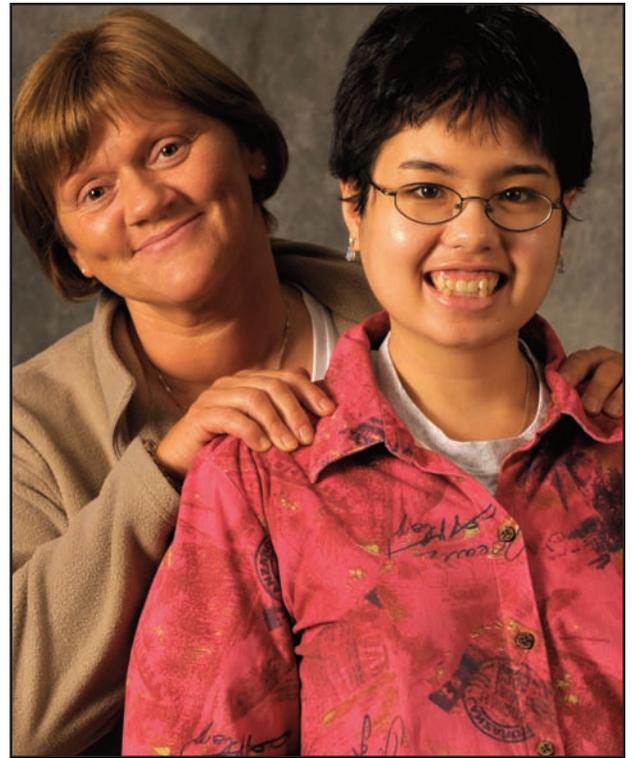
In 2008, the New York State (NYS) Office of Mental Retardation and Developmental Disabilities celebrated its 30th anniversary as an autonomous agency. Born out of the need for a single agency to be accountable for implementing the reforms of the landmark 1975 Willowbrook Consent Decree for persons with developmental disabilities, OMRDD used that mandate to move nearly all individuals with developmental disabilities from its institutions and create a comprehensive network of community-based programs and services unmatched in our nation. Initially partnering with voluntary agencies and families, later strengthened and informed by a growing self-advocacy movement, OMRDD, over three decades, dramatically expanded its services and reach. The citizens of New York, with disabilities and without, can be proud of the developmental services system we have built together.

From time to time, we need to reflect upon the fact that it was not always so. In the 1970s, families were routinely advised to institutionalize their young child with a developmental disability in a state school so as to provide necessary care and not “disrupt family life.” The 1980s and 1990s ushered in rapid changes in the kinds of supports and services available: Family Support Services (FSS), group homes and apartments, day programs, work programs, transportation, and respite, all services that emphasized community-based care over institutionalization. With each passing year, the system grew in resources and complexity. In 1991, OMRDD initiated New York’s Home and Community Based waiver under the federal Medicaid program, which permitted a more individualized set of community supports and services to be offered through Medicaid, planned specifically for each person.

In the mid-1990s, OMRDD adopted the emerging concept of person centered planning as the new gold standard of care, and over the past decade we have seen people with developmental disabilities, their families and friends, agencies, and practitioners explore the meaning of “person centeredness” and how they can apply these concepts in the work they do. Today we have a far greater understanding of the importance of this concept and of people’s desires to have more control over their supports and services. OMRDD has demonstrated its commitment to person centered principles by adopting “Putting People First” and “Helping People Live Richer Lives” as part of its logo and mission — the first defining the process of developing services and supports, while the other concisely capturing the outcomes we all strive for in supporting people with developmental disabilities.

Systems Transformation

Like evolution in the natural world, OMRDD’s evolution was not linear but rather has been marked by dramatic and rapid leaps. In retrospect, change often seems to have been spurred on by crisis, combined with a critical mass of stakeholders who agree on a new and better approach. At OMRDD, challenges to the status quo have always been viewed as opportunities to do things better. Over these past 30 years, we have witnessed many system wide improvements, from the closing of institutions, to the establishment of a variety of community-based living arrangements; from segregated





educational and work environments, to those integrated in the community; from families with no options, to a broad range of family supports; from specialized and often stigmatizing services, to natural and community-based supports; and most importantly from a “medical” model of disabilities based on deficit thinking, to a “support” model that celebrates the capacities and contributions of all people to be fully integrated into society. The emergence of self-advocacy, and the emphasis on full human rights and active citizenship for all people, continues to alter our expectations about human potential. We are often amazed and delighted by what people with developmental disabilities - with proper supports - can accomplish, and what they teach us about ourselves and our society.

Evolution does not stop -- it cannot be stopped. Today OMRDD is on the threshold of another significant shift in how we make certain services and supports available to people with developmental disabilities. For the past several years, OMRDD and the provider community have demonstrated the viability of several emerging support models, including: individualized and person-controlled housing, enhanced supported work and career volunteerism, expanded family supports, and self-directed services based on individualized budgets, and circles of support. These more person centered and individualized alternatives, supporting people to lead more typical lives in their communities, represent the path that OMRDD and its provider network must take in order to keep pace with customer demand for more choice, control, and community membership.

Self-advocates have made it clear that they want “a life” and not “a program,” and a real life is based upon the four primary person centered outcomes that support our mission: a home, a job or other activities that allow people to contribute to their community, meaningful relationships, and good health. OMRDD intends to do everything it can to deliver on this promise by transforming the service system once again in support of these contemporary outcomes. Under the new leadership of Governor David A. Paterson and Commissioner Diana Jones Ritter, OMRDD has already begun this shift with an approach to agency management and business practices that reflect high performing government. OMRDD has become more customer-driven, and is committed to constantly assessing what people with developmental disabilities, their families, and their providers request and need to be successful. That means focusing on quality of life outcomes. We need to focus more on how services and supports lead to actual improvement in people’s lives, as they define them. We need to count smiles, not just service units delivered.

A Challenging Environment

It will come as no surprise to OMRDD’s constituencies that New York, like nearly all other states, is undergoing a period of fiscal uncertainty and tight budgeting. OMRDD is viewing this situation as a challenge which it will meet by becoming more economical and efficient, while improving quality and continuing to expand the numbers of people it serves. OMRDD takes seriously its obligation to be a good steward of the public’s trust and resources. OMRDD will emphasize equity, fairness, and cost-consciousness, values it has always embraced but are even more significant today in a time of lean budgeting. OMRDD is encouraging a dialogue with self-advocates, families, providers, employees, and other stakeholders about what each of us can do to create equity, efficiency, and cost-effectiveness throughout our system. This is a communal responsibility, and people will be encouraged to share resources and use them prudently. OMRDD firmly believes that if we all work together, we can continue, and further build upon, our tradition of caring, inclusiveness, and excellence, despite the challenges that lay before us.

There is an expectation that government is responsive and responsible to the public, and business is performed in a transparent and public manner. OMRDD fully supports this principle of government accountability and welcomes the opportunity to demonstrate progress towards its established priorities through increased use of performance metrics reporting. Included in this year’s Plan are stated outcomes of accomplishments anticipated over the course of the next five years and measures for determining progress towards these goals. OMRDD is committed to becoming more visible in charting our progress, and in developing additional metrics and analytic tools to demonstrate specific progress towards identified priorities and expected outcomes. A broad array of methods for evaluating services in the future will be employed, and OMRDD will document the status of the planned activities through the use of user-friendly web-based public reporting, as well as more traditional methods of communication.

Chapter 2: Mission, Vision, Values, and Guiding Principles

The Mission Statement

We help people with developmental disabilities live richer lives.

The Vision Statement

People with developmental disabilities enjoy meaningful relationships with friends, family and others in their lives, experience personal health and growth, live in the home of their choice, and fully participate in their communities.

More specifically, OMRDD is committed to achieving the five following basic outcomes for people with developmental disabilities:

- **Person First.** People who have developmental disabilities have plans, supports, and services that are person centered and as self-directed as they choose.
- **Home of Choice.** People who have developmental disabilities are living in the home of their choice.
- **Work or Contributing to the Community.** People who have developmental disabilities are able to work at paying jobs and/or participate in their communities through meaningful activities.
- **Relationships.** People who have developmental disabilities have meaningful relationships with friends, family, and others of their choice.
- **Good Health.** People who have developmental disabilities have good health.

These five outcomes provide the framework for the OMRDD Comprehensive Plan for 2008-2012.

The chapters that follow describe the key activities OMRDD will engage in to help people realize their personal goals related to home, community contribution, relationships and health. In addition, another chapter lays out those cross-cutting supports and activities necessary to support these key outcomes regardless of outcome focus, whether home, work, relationships, or health.

Values

Values describe how we as employees of OMRDD interact with the individuals we serve, families, staff, the community and each other:

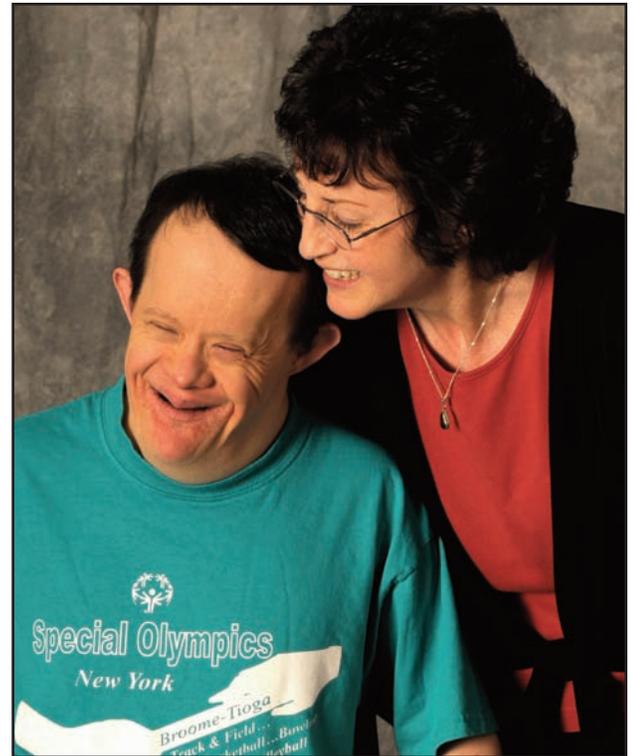
Compassion - The capacity to appreciate what others think and feel.

Dignity - The recognition of the worth of each person and the treatment of individual rights and preferences with respect, honor, and fairness.

Diversity - The celebration, respect and embracing of the differences among us because these differences strengthen and define us.

Excellence - The continual emphasis on innovation, increasing knowledge, and delivering the highest quality supports and services.

Honesty - The foundation on which trust is built and truth is communicated.



Guiding Principles

Guiding principles frame how OMRDD conducts its business:

Put the person first - People with developmental disabilities are at the heart of everything we do, and this person-first ethic is embodied in the way we express ourselves, and in the way we conduct our business.

Maximize opportunities - OMRDD's vision of productive and fulfilling lives for people with developmental disabilities is achieved by creating opportunities and supporting people in ways that allow for as many as possible to access the supports and services they want and need.

Promote and reward excellence - Quality and excellence are highly valued aspects of our services. Competency is a baseline. We find ways to encourage quality, and create ways to recognize and incentivize excellence to improve outcomes throughout our system.

Provide equity of access - Access to supports and services is fair and equitable; a range of options is available in local communities to ensure this access, regardless of where in NYS one resides.

Nurture partnerships and collaborations - Meaningful participation by people with developmental disabilities strengthens us. OMRDD staff and stakeholders create mechanisms to foster this participation. The diverse needs of people with developmental disabilities are best met in collaboration with the many local and statewide entities who are partners in planning for and meeting these needs, such as people who have developmental disabilities, families, non-profit providers, communities, local government, and social, health and educational systems.

Require accountability and responsibility - There is a shared accountability and responsibility among and by all stakeholders, including individuals with disabilities, their families, and the public and private sector. OMRDD and all its staff and providers are held to a high degree of accountability in how they carry out their responsibilities. We strive to earn and keep the individual trust of people with developmental disabilities and their families, as well as the public trust. Creating a system of supports that honors the individual's right to be responsible for their own life and accountable for their own decisions is of paramount importance.

Chapter 3: A Snapshot of Where We Are Today

Developmental Disabilities

To understand the service system for people with developmental disabilities in NYS, 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; and
- (b) originates before such person attains age twenty-two; and
- (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 perform everyday activities, such as an assessment of adaptive behavior and independence skills, is necessary to determine eligibility regardless of the diagnosis of the disability.

To increase the quality and consistency of eligibility assessments and awareness of the eligibility process and standards, OMRDD issued the following guidance: *OMRDD Advisory Guidelines--Determining Eligibility for Services: Substantial Handicap and Developmental Disability (12/2001)*, a clarifying Memorandum (8/2002), and an Important Facts Sheet (6/2002). These documents are posted at the OMRDD website (www.omr.state.ny.us) making them available to individuals, families, providers, and clinicians alike.

Using a widely accepted NYS population projection from the 2006 U.S Census Bureau of 19,306,183 and a developmental disabilities prevalence rate of 1.58% based on a large, national health survey (see MR/DD Brief April, 2000 from Research and Training Center on Community Living, University of Minnesota), there are an estimated 305,000 New Yorkers with a developmental disability. Given the recent studies suggesting that there are many more people with Autism than previously believed, there is more uncertainty about prevalence numbers than in the past. OMRDD is currently reviewing prevalence issues and in future plan updates the question will be re-visited. Until then, our best estimate is that over 300,000 people living in NYS have a developmental disability.

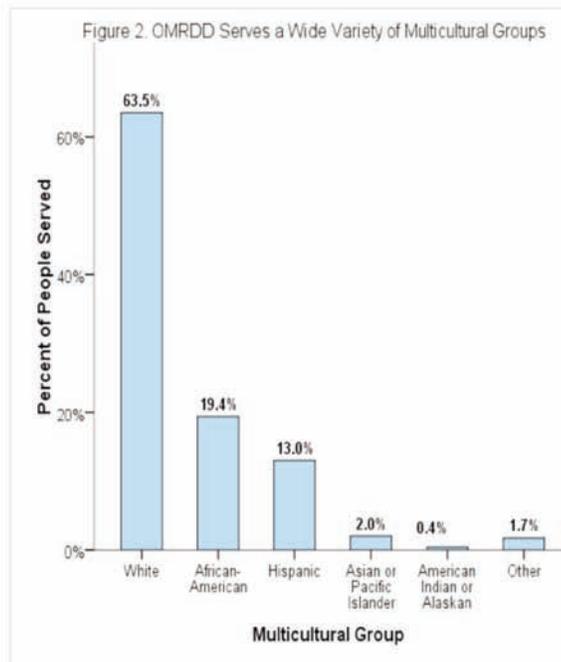
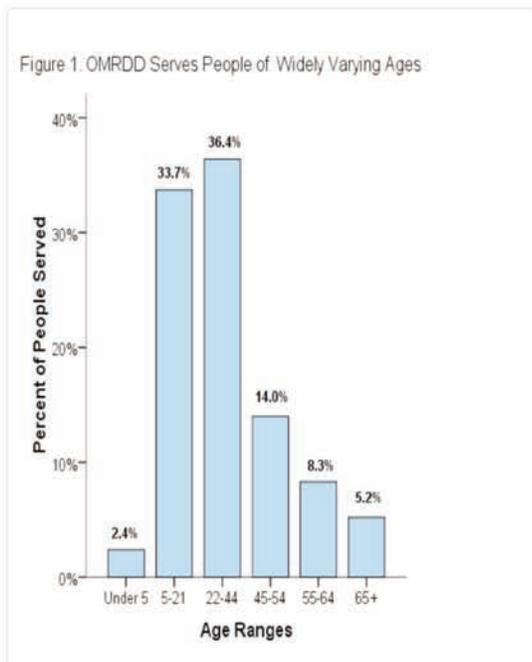
There is, of course, a large difference between the number of people who are projected to have developmental disabilities and the number who participate in developmental services. There are several reasons for this:

- Many people receive supports and/or services in human services sectors other than developmental services.
- 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 service agencies and resources.
- Some people are registered through needs assessment efforts, but do not yet receive services.

Where We've Been and Where We're Going

OMRDD is a young agency, born in 1978, and we have traveled a long way in just 30 years. In this section three important aspects of OMRDD's historical path are described: the people we serve, the foundation of our mission, and the services and supports we provide. (For a complete description of the supports and services available through OMRDD and its network of providers, please consult the OMRDD website at <http://www.omr.state.ny.us/>.) Trends in these three critical dimensions remind us of where we started and point to where we're going.

The people we serve. OMRDD serves a diverse, growing and changing group of families and individuals. At the core is the diversity of our people. For example, Figures 1 and 2 demonstrate two fundamental aspects of this diversity. First, Figure 1 shows the distribution of age among all individuals served by OMRDD. The age range is great, from near birth to people who have lived into their 90s, and reminding us that services must be developed that are sensitive to the differing needs of this broad age spectrum.

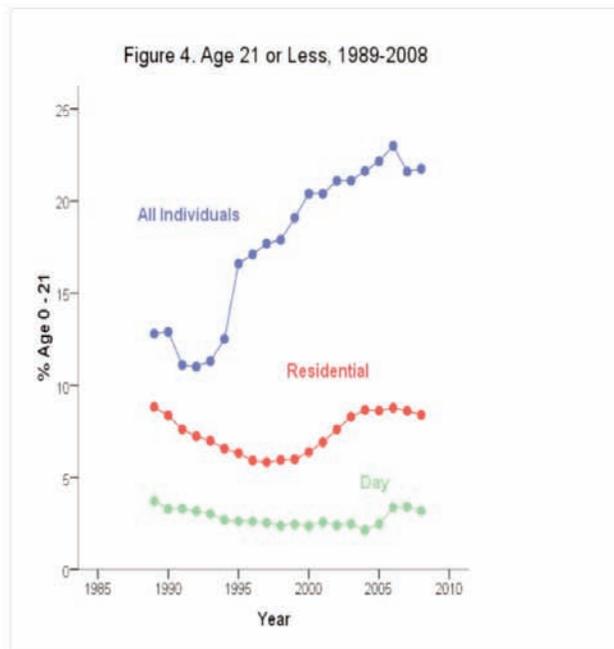
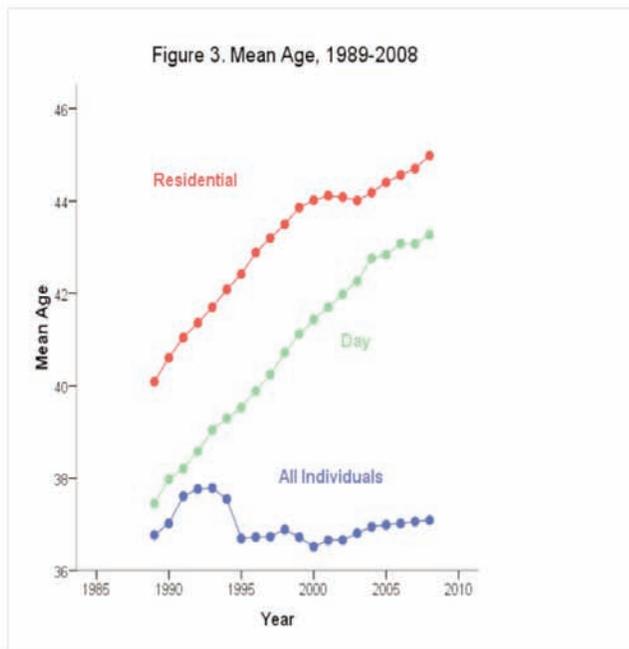


Over a third of the people served are young individuals less than age 22, a constituency with the potential to re-focus OMRDD's services and supports. And the largest group, 36.4%, consists of young adults ages 22-44. More than one fourth of the people served (27.5%) are 45 or older, up more than 10% since the last plan was developed just four years ago, in 2004.

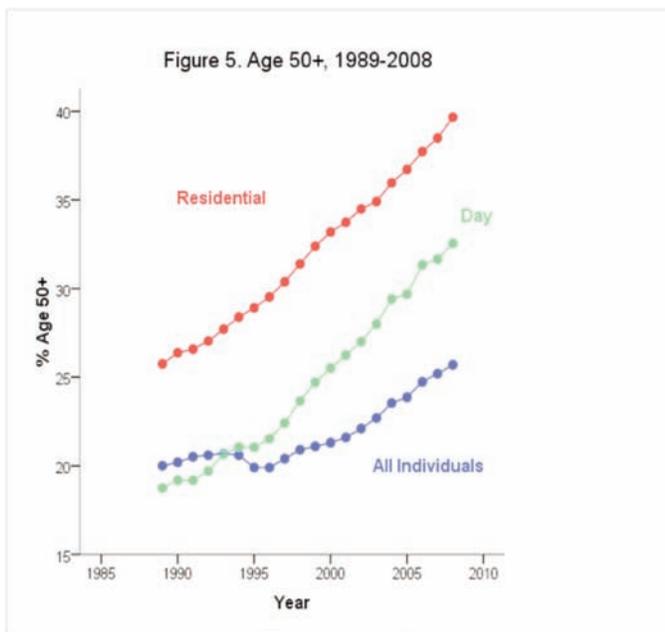
Figure 2 describes the multicultural distribution of people served by OMRDD, a second key element of the diversity of the people served. OMRDD serves an array of ethnic groups with a determination to address all the cultural differences in a state as large and diverse as New York. As Figure 2 shows, better than one in three (36.5%) of the individuals served are from federally defined multicultural groups. Overall, this is in balance with New York's general population. Further, the multicultural representation among the people served has been steadily rising, increasing by better than 10% in the last decade as OMRDD reaches out to New Yorkers of all multicultural groups.

Figure 3 shows clear positive trends in aging for both residential and day participants, and individuals in both settings are aging at roughly the same pace. People living in residential settings lead this trend, with the mean age increasing from around 40 in 1989 to almost 45 in 2008. Sometime in the next 20 years the average age among individuals living in an OMRDD residential setting will reach 50 years of age. The likely continuation of this longstanding trend has major implications for support levels for these settings.

Over the thirty years of OMRDD's existence, the diverse and changing needs of individuals and families have



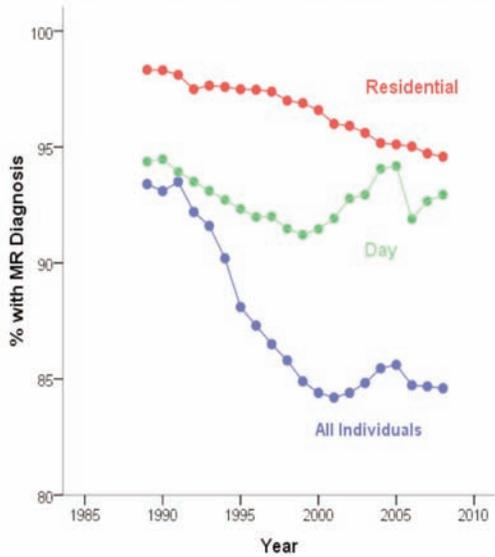
In contrast, Figure 3 also indicates that among all individuals participating in OMRDD services and supports there is little evidence of an age trend. Figure 4 clarifies why mean age is not increasing among all individuals served: the increasing levels of younger people among all individuals served. As the plot shows, young people are still relatively rare in both residential and day settings. Fewer than one in ten of the people living in OMRDD-certified residences are less than age 22, a level that has varied somewhat over the years but has not trended. Similarly, since the vast majority of young people are principally served by the educational system, individuals less than age 22 are even less common in the day sector and likewise trendless. Among all individuals served, however, young people have been steadily increasing for years, to the point that now better than one-in-five of the people served are less than 22 years old. This trend has profound implications for OMRDD and drives the need for family supports, among other things.



Finally, as Figure 5 demonstrates, the growing presence of older people among those served by OMRDD is a clear increasing trend in all three groups: all individuals, out-of-home residents and day participants. However, the pace of the increase is especially notable in residential and day settings, mirroring the increases in mean age seen earlier. Among people living in residential settings, about 40% are now 50 years of age or greater, and the trend has been steady for almost 20 years. In day services and supports, the presence of older individuals is at a lower level, but the trend, if anything, is steeper. The milder trend in the percentage of older people in the “all individuals” group explains why the growth in young individuals “averages out” the growth in older individuals, resulting in the lack of any clear trend in average age as seen above in Figure 3.

In sum, the people supported by OMRDD are, at once, becoming younger and older, depending on which segment of OMRDD services is being discussed. In residential settings, the average age is increasing at a pace where the average resident will be 50 sometime in the next 20 years. At the same time, the rapid expansion of programs to support families at home that we will examine shortly has led to more young individuals so that the mean age of all individuals served is fairly stable.

Figure 6. People with MR Diagnosis, 1989-2008



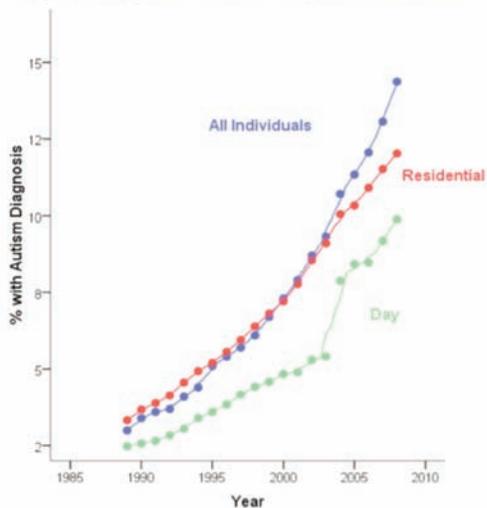
OMRDD also serves people with more and more diagnostic diversity. For example, a clinical diagnosis of Mental Retardation (MR) was once a universal factor among people served by OMRDD. Figure 6 shows that while MR is still almost universal among residential participants, the prevalence has steadily decreased over the last twenty years. The trend among day service participants is less clear and a little more erratic. However, there is a marked decline in MR clinical diagnoses among all individuals served, with the percent of people with MR dropping from nearly 95% in 1989 to around 85% in 2008. This trend speaks to a broadening array of developmental issues among the people served, as OMRDD reaches out to serve and support individuals in accordance with their desires and needs.

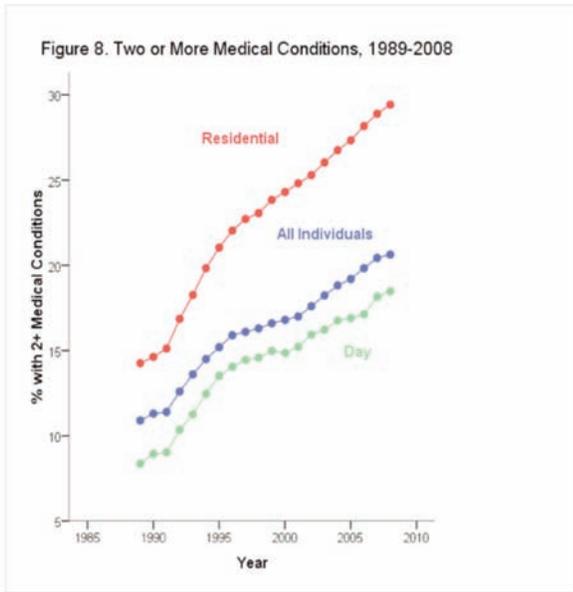
No OMRDD diagnostic trend over the last two decades has been more significant than the increase in the percentage of people with autism and Autism Spectrum Disorder (ASD) served by OMRDD.

Though not as explosive as the growth reported by some states, the presence of autism has nonetheless increased substantially over the last twenty years. Among all individuals served, the percentage of people with an autism diagnosis has increased by more than 350% among all individuals, from about 3% in 1989 to more than 14% in 2008.

Two other things are important about the growth of the autism diagnosis. First, the “all individuals” group has emerged as the leading edge of autism growth, slightly eclipsing the residential sector and suggesting that the trend may be driven by higher rates among people living at home, a contention supported by much higher diagnostic rates among younger age groups served by OMRDD. Second, the trend may be continuing at an increasing rate, meaning that much higher rates of autism diagnosis may be ahead.

Figure 7. People with an Autism Diagnosis, 1989-2008





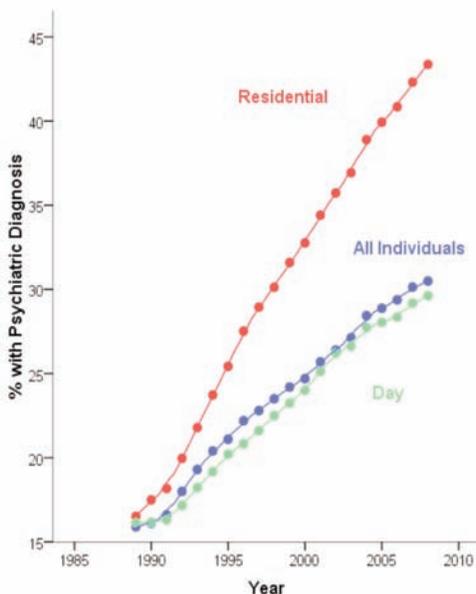
People served by OMRDD also present a variety of challenges secondary to their developmental issues. These secondary issues often drive the need for resources as much, or more as any developmental challenges. The final two figures address two very important secondary challenges faced by the people served by OMRDD. First, Figure 8 shows the trend in the percent of people who have two or more medical conditions, one indicator of medical complexity. All three groups show a trend toward more medical involvement, but the pattern is most dramatic among people living in a residential setting. In 1989, a little less than 15% of residents were, by this measure, medically complex; that percentage had nearly reached 30% by 2008. Not surprisingly, the residential trend tracks closely with the mean age trend in that setting.

The other two settings also show clear signs of increasing medical complexity, though at much lower levels and slower rates. Again, the all individuals group raises an interesting question. If medical complexity is strongly driven by aging, why the increasing trend among all people served? One answer is that families with

members who have significant medical issues are increasingly turning to OMRDD for support and, with the advent of Home and Community Based Services and Care at Home waiver programs and other supports, these families are able to keep their children at home.

Finally, Figure 9 shows another defining OMRDD issue of the last twenty years—the level of dual (developmental and psychiatric) diagnoses among people served by OMRDD. Though much more pronounced in the residential setting, all three groups show the growing presence of psychiatric issues. Among residents, 16.5% of individuals had a formal psychiatric diagnosis in 1989, compared to about 43% in March, 2008—an increase of better than 150%. The trend in the other two groups is slower but significant levels are represented in both settings.

Figure 9. People with a Psychiatric Diagnosis, 1989-2008



In conclusion, OMRDD serves a complex and changing group of people. The individuals served are becoming, at once, younger and older. At the same time, the expansion of programs to support families has led to more young people being served so that the mean age of all individuals served has been fairly stable over the last two decades. This masks significant aging proceeding among people living in OMRDD’s core residential system who will need more age-related supports in future years. The people we serve are also becoming more diverse in diagnoses and challenges. For example, though the level is still high, the MR diagnosis is becoming less prevalent over time. There are also pronounced trends in two important diagnoses. First, autism is increasingly prevalent, more than tripling since 1989. Second, the percentage of people with a dual diagnosis (a developmental diagnosis and a psychiatric diagnosis) is rapidly increasing, from about 16% in 1989 to over 40% among individuals living in residential settings. Finally, another important trend is the increasing presence of individuals with complex medical needs,



particularly in residential settings, where the percentage with two or more medical conditions reached more than 40% in 2008. These changes in the people we serve, along with a rolling revolution in ideas about where and how to serve them, have moved OMRDD in new directions and will continue to do so.

The growth and reconfiguration of services. Four important trends have defined OMRDD’s system of services and supports. First, over the last four decades a large institutional system (nearly 28,000 residents in 1968) has been dismantled (only 1,560 remained as of March 31, 2008, and most of them reside in special units designed to address very challenging behavior). Second, along with institutional decline there has been an emergence of a vast, statewide system of community services, with a range of residential, day and family support options. Third, OMRDD has downsized the community residential system, part of an effort to make services smaller and more individualized. Fourth, OMRDD has, through the Home and Community Based Services (HCBS) waiver, expanded day services and paved the way for more individualized services for the people we serve. OMRDD has begun to re-define itself yet again by promoting highly individualized, often participant-directed, services. This is where we are heading, but first here is some history.

Figure 10. Institutional Trends, 1968-2008

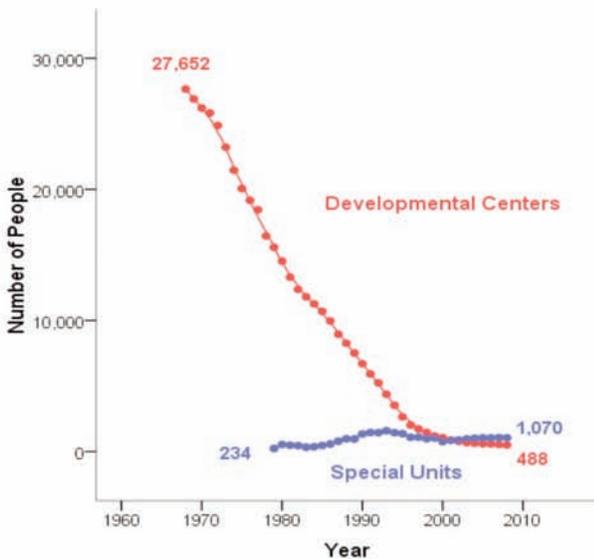


Figure 11. Institutional Decline and Community Growth, 1980-2008

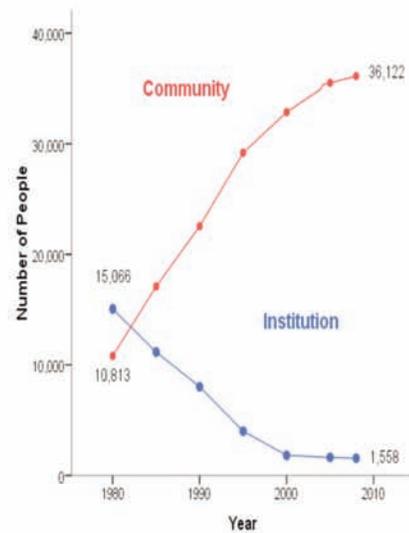
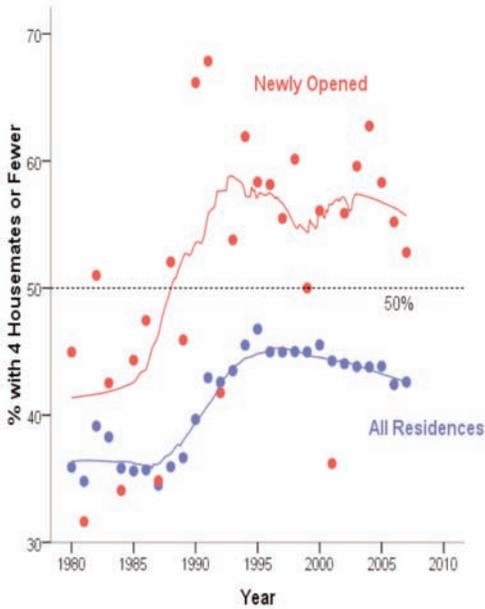


Figure 10 portrays the OMRDD signature trend for the last four decades. Developmental Center (DC) enrollments declined from a peak of nearly 28,000 individuals in 1968 to a low of 488 in March of 2008, a decrease of 98%. Over time, however, special units designed to respond to the needs of people with special behavior challenges were created. Figure 10 shows how in the midst of a dramatic decline in general DC unit residents, the special populations have been stable or, at times, even an increasing presence. As of 3-31-2008, special units accounted for almost 7 in 10 (68.7%) of the 1,558 people living in institutional settings. The special units are designed to address an array of special behavioral challenges.

The data in Figure 10 account for only half of the story. The decline of institutional living was accompanied by the creation, one home at a time, of a large, statewide network of community programs of various types. As shown in Figure 11, the community living numbers have increased as the institutional numbers have fallen. Since 1980, community residential programs have grown 140%, from 10,813 in 1980 to 36,122 in 2008. In this period, the community sector added almost 25,000 openings, much more than necessary to meet the demands of shrinking and closing institutions. These opportunities were created to address the desire of families for a place for their children.

Figure 12. Smaller Residences in the Community



Even before deinstitutionalization neared completion, OMRDD started downsizing the community residential system by reconfiguring existing programs and developing new, smaller residences. This has been the second key trend in OMRDD’s services and supports. Figure 12 shows one aspect of this trend by plotting the percentage of residences designed for four people or fewer, a good indicator of the prevalence of smaller residences in the years from 1980 to 2008. We plot the data for two groups of community homes, those newly opened in a given year and all residences in operation that year. The pattern is clear: for both new and existing homes smaller programs were rare until the mid-1990s, when they became much more prevalent before leveling off in recent years. Among newly-opened homes the picture is much more variable, but for most years since 1990 at least half of the programs opened served four people or fewer. Since the mid-90s the full community residential system has hovered at a little over 40% of smaller residences. This trend toward smaller residences in the community is expected to continue.

Along with the growth of more and smaller community residential options for people with developmental challenges, an array of options for day supports and services has been created. These options range from comprehensive treatment services, to job preparation skill training, to supported jobs, to activities for older people with developmental disabilities. Figure 13 shows the dramatic expansion of day activities. Since 1990 the total number of day participants (in blue) has increased by 86%. Behind these large and growing day enrollments there is a continuing reconfiguration of day options made possible by OMRDD’s HCBS waiver. These changes have made more and more individualized opportunities available to more and more people.

Figure 13. Number of Day Participants

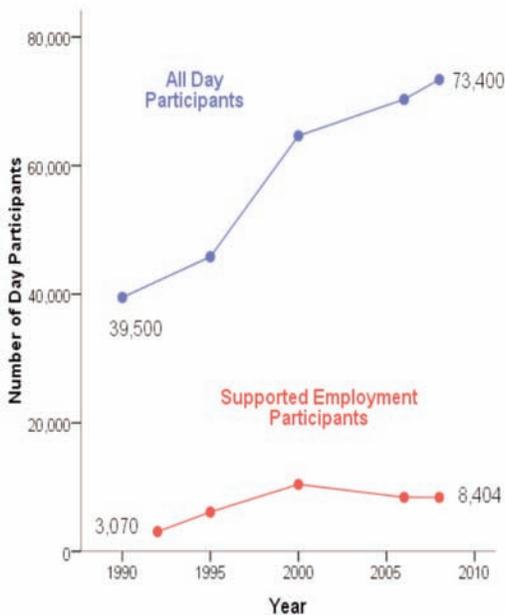
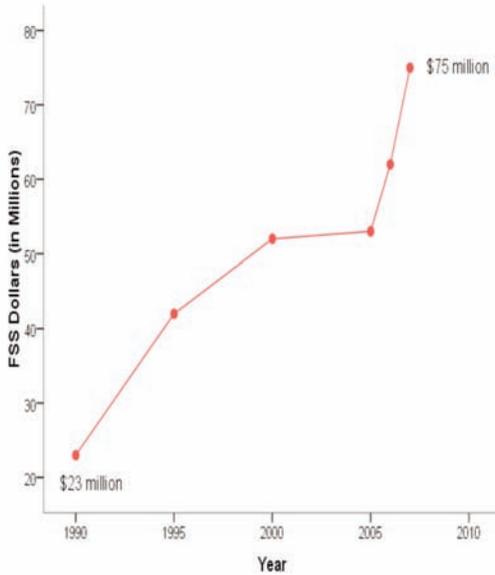


Figure 13 also highlights (in red) the trend in the all-important jobs sector. Supported Employment experienced steady growth to about 2000 when a reorganization of the program resulted in the transfer of many enrollees who didn’t meet OMRDD’s eligibility criteria to the NYS Education Department’s (SED) Office of Vocational Educational Services for Individuals with Disabilities (VESID), where their needs were more appropriately addressed. Since then, enrollments in Supported Employment have stabilized at a little over 8,000. A new OMRDD initiative is now in place which should lead to a return to growth in work opportunities, a major strategic imperative for OMRDD’s future.



Figure 14. Family Support Dollars (Millions), 1995-2007



In addition to an expanding range of community participation options, OMRDD also provides a broad array of supports for families and individuals living at home, promoting OMRDD’s cornerstone policy of keeping families together as long as possible. These supports include a variety of respite programs, recreation, reimbursement, counseling, parent/ caregiver training, and more. Figure 14 shows that the increase in Family Support Service (FSS) dollars has accelerated over the last few years, and since 1990 FSS funding has increased by better than 225%, from \$23 million in 1990 to \$75 million in 2007.

The advent of the HCBS waiver in 1993 marked a new era of services, giving OMRDD new flexibility in the design and delivery of services. The goals of the waiver were to serve more people with a wider range of community-based services that were more individualized and less expensive than institutional care. The HCBS waiver provided the framework within which many of the ideas of individualization and “putting people first” have been put into place, including the implementation of person centered planning across the State, developing “day programs without walls,” developing self-directed programming, and promoting the view of people with

disabilities as citizens contributing to their communities.

Figure 15. People Enrolled in HCBS Waiver, 1993-2008

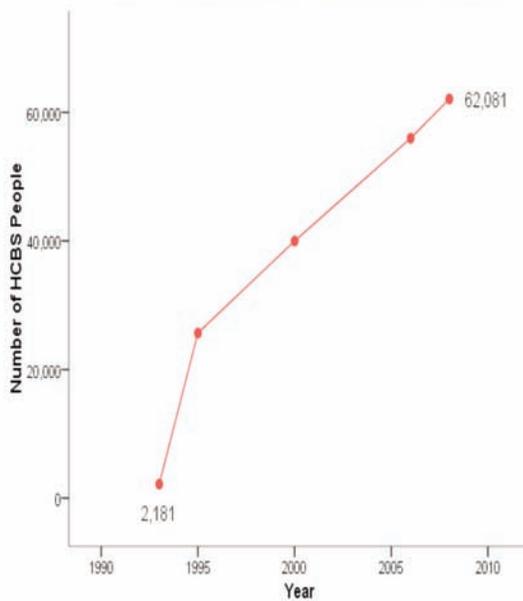


Figure 15 describes the growth of the HCBS waiver. Beginning in 1993 with the enrollment of 2,181 individuals, the waiver has grown to 62,081 people in 2008. This represents an expansion of almost 60,000 people in the last 15 years.

In a more individualized world with more personal choices to be made, service coordination is the key to creating an appropriate set of services and supports for individuals with developmental challenges. Accordingly, Medicaid Service Coordination (MSC) has expanded at a rapid pace. And, as satisfaction data collected as a part of the process of getting a new home demonstrates, the families and participants of NYS-CARES are very satisfied with the way service coordinators help them negotiate a large and complex system of services and supports. OMRDD’s goal is to broaden that level of satisfaction to all MSC roles.



Figure 16. People Getting Service Coordination, 2000-2008

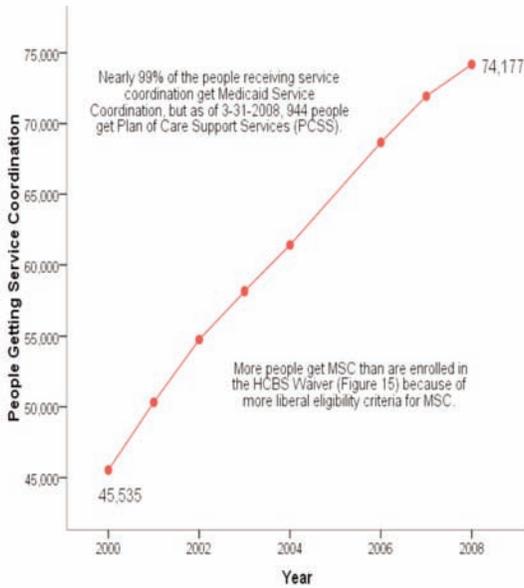


Figure 16 portrays the growth in Medicaid Service Coordination (MSC) since 2000, showing a robust expansion of 63%, from 45,535 in 2000 to 74,177 in 2008. Two things should be noted. First, while almost all individuals get service coordination under the MSC rubric, a small number (944 as of March 31, 2008) receive their service coordination through Plan of Care Support Services, a time-limited service for development of a plan of care for people who do not want ongoing service coordination. Second, the service coordination numbers reported in Figure 16 exceed the total HCBS numbers reported in Figure 15. That is because the eligibility requirements for MSC are more liberal than those of the HCBS waiver.

Chapter 4: Person First – Person Centered and Self-Directed Supports

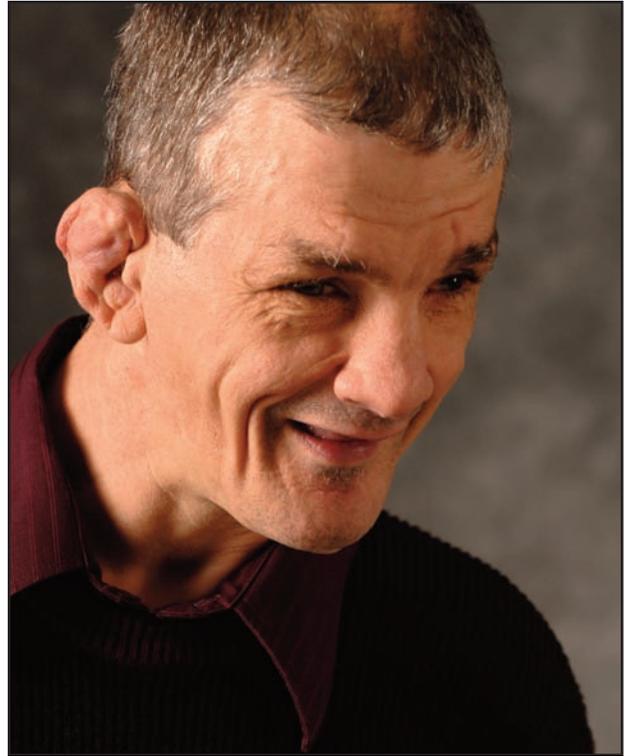
The evolution of NYS’s system of developmental services, and of OMRDD itself as an organization, is at a critical juncture. At present the service system is still largely characterized by congregate service models that assist people in groups and cannot easily accommodate highly individualized service plans. As noted earlier, OMRDD is actively promoting a transformation of the service environment from the present system to one in which the people it serves are able to readily gain access to person centered supports, and that those supports will allow for a broad range of individualization and choice. OMRDD’s “person first” approach will build on recent successes in self-determination, and will include a range of flexible supports and methods of assistance that can be customized to more closely match the personal goals and needs that people express.

The starting point for many of the service decisions people must make will be a person centered planning process, one that enables people to consider their life goals and priorities while being informed about the menu of services and supports available. The system of the future will assist people to take as much control of the design and direction of those services as they reasonably desire, and will incorporate the flexibility needed to accommodate to real people’s lives as they change and grow. This dynamic, person centered vision of services and supports, infinitely individualizable, will enable more and more people with developmental disabilities to lead richer lives and in fact to achieve “lives of distinction.”

Lives of Distinction

OMRDD believes that every person with a developmental disability has a distinctive contribution to make to the world. By supporting people to develop these contributions and make connections with people and communities, we help them to become valued and respected by others. Contributions become visible and people take pride in their accomplishments. But, even more important, the lives of the people surrounding them are enriched by their contributions. Building relationships through work, volunteerism, and participation in community life is at the core of building “lives of distinction” (a term which OMRDD has appropriated from the work of Beth Mount, Ph.D.)

OMRDD is proud of the efforts of agencies to help people with disabilities become fully included as community members in their own neighborhoods. Incredible stories of success are heard all over the State. However, more needs to be done to provide high quality individualized and person centered supports. OMRDD will continue to support activities that foster desirable and sustainable changes in agency cultures that support lives of distinction. OMRDD also intends to increase opportunities to provide plans, supports and services that are person centered and as self-directed as people choose, so that they can have the home of their choice in the neighborhood of their choice, contribute to their community in preferred jobs, artistic endeavors or activities, have good health and ultimately, have meaningful relationships with friends, family, co-workers, and others of their choice.



The future efforts of OMRDD to more effectively offer the supports, services, and programs that people who have developmental disabilities and their families have requested and need is closely tied to the capacity to offer person centered, customized services. OMRDD will continue to support its full range of programs and services, but information gathered from individuals and families has made it clear that the agency must do a better job of offering person centered and more customized supports and services, as well as offering more opportunities for individuals and families to self-direct those supports and services to the extent they desire. This new emphasis reflects a national movement towards increased choice, control, and self-direction in service delivery. (Throughout this Plan, the term “self-direction” is used to indicate a service arrangement in which the person, his or her family, or other people identified by the person as his or her representative, are in control of resources and can choose from a variety of service delivery options.)

OMRDD’s management assessment strongly suggests that through changes to its financial platforms, administrative infrastructure, and business practices, these services can offer both equity of access and a better match between what people with developmental disabilities and their families need and desire in order to live the lives of distinction they deserve. National research also indicates that this better balance of supply and demand for services, especially when connected with more opportunities for self-direction, leads to more people being served, increased customer satisfaction, and improved efficiencies.

The emerging framework for this new approach is related to OMRDD’s current Consolidated Supports and Services (CSS) model. In June 2001, OMRDD implemented this service option to enable individuals with developmental disabilities to create their own plans and administer their own individual budgets, as an alternative to receiving traditional rate-based services through an agency. This was a significant departure from OMRDD’s existing fiscal and administrative framework. CSS, a self-directed service option under the Home and Community Based Service (HCBS) waiver, represents one path for individuals with developmental disabilities in NYS to pursue self-determination using an individualized budget to fund necessary supports and services in conformance with an approved plan of care. The data from a 2007 survey of CSS participants indicate that CSS had the desired effect of empowering individuals to make decisions in their lives and to participate in community life through more mutual and organic relationships. Increases in friendships, community involvement, personal growth, and satisfaction with services were also identified as outcomes of participation in CSS. Most importantly, people indicated high levels of satisfaction with the choice and control that CSS provides and have remained healthy and safe in a self-directed environment.

The concept of individualized resources, no matter how they are structured, allows participants to hire their own staff or purchase the supports and services they need to live responsible, productive, and rewarding lives within their chosen communities. Individual resources should be portable, meaning that they “follow” the person. Individual resources allow access to more person centered supports and services which include, but are not limited to: smaller homes (including non-certified living arrangements), supportive Individual Residential Alternatives (IRAs), family living, shared living, at-home residential habilitation, crisis services, CSS, Individual Support Services (ISS), family supports, employment, and innovative day activities like “day habilitation without walls.”

This self-directed service option has proven to be versatile, cost-effective, and responsive to the needs of individuals. OMRDD has discovered, however, that the current CSS design seems to appeal more to individuals who are willing and able to assume the significant responsibility for the administration and oversight of their services. Presently, despite notable monthly growth, only 500 of the 62,000 people receiving services under the HCBS waiver are participating or applying to participate in CSS. In an effort to make self-direction a more viable option for a larger number of people receiving services, OMRDD will promote a number of strategies in addition to CSS to refine and redesign these service opportunities in a way that will be simpler and easier for people to access and self-manage. Strategies undertaken will be designed to:

- **Increase the ability of individuals and families to identify their service needs and access the financial resources necessary to pay for these supports.** OMRDD will develop mechanisms to dramatically increase opportunities people have for more choice and control over the supports and services they require. CSS has shown that when people and families identify and have responsibility for self-directing their supports they experience greater satisfaction with the services they receive. Opportunities will be enhanced, through options such as self-directed At Home Residential Habilitation and Agency-with-Choice (AWC), to develop several approaches to self-directed services and individualized budgets. (Agency-with-Choice is an



arrangement in which a person or family selects an agency to assist in the management of an individualized portable budget and provide some or all of their services.)

- **Increase opportunities for meaningful employment and volunteerism.** OMRDD will continue to pilot innovative ways to provide supports for individuals so they can work in competitive employment and job development settings. OMRDD also continues to explore models to support people interested in pursuing continuing education at universities, community colleges, and vocational training settings. Lastly, OMRDD seeks to provide assistance to individuals interested in entrepreneurial and self-employment endeavors. In all instances, it is vital to encourage opportunities within community settings that lead to the development of marketable skills which may result in competitive employment at some point in the future.
- **Increase provider capacity to offer more individualized, customized, and person centered options.** Many people indicate that what they are seeking is “a good agency that will listen and be responsive to them.” In order to ensure that people are able to choose among all the person centered, customized service options OMRDD will be working with its network of providers to re-examine our roles and business practices. Agencies will be a major resource in support of self-directed services. Providers have expressed interest in developing and offering individualized supports for people they serve, but how to actually begin remains a challenge. OMRDD and the NYS Developmental Disabilities Planning Council have provided funding, administered through the NYS Association of Community and Residential Agencies, to fifteen agencies statewide to participate in a “Learning Institute” designed to develop the organizational cultures and service designs necessary for promoting and supporting individualized services. These agencies will assist OMRDD in determining best practices in individualized service delivery and activities that help sustain the organizational cultures necessary to nurture individualized approaches. Future institutes for developing so-called “communities of practice” around individualized services methodologies are also under consideration.
- **Development of streamlined practices.** The most elegant and effective services are of no value if one has to wait an excessively long time to gain access to them. This is particularly true for people who literally cannot wait – they are graduating from school, seeking a job, in crisis at the family home, or in psychological or physical peril. Often, comprehensive “24/7” services take a long time to put in place, in part because of their complexity, but also because of the lengthy procedures that have evolved over time that control entry. Such a system, in not being responsive and proactive, leads to unrecognized human suffering and cost-inefficiency. Expediting access to all services – but especially to highly individualized supports that can be deployed rapidly to rent an apartment, support someone in a job, or deal with a crisis - is a high priority in OMRDD’s reengineering of the system. If it is to be successful and customer friendly, system transformation must result in, among other imperatives, a more rapid and streamlined approach to service delivery.
- **Navigating person centered supports.** Current efforts in self-directed and highly individualized service approaches show that most people’s major needs are in the areas of (1) staff supports, (2) transportation, and (3) a room and board subsidy (for individuals who wish to live on their own). OMRDD also has learned that most people and families who self-direct need additional help and guidance, especially in areas related to plan reviews and revisions, ongoing documentation, and other areas of Medicaid compliance. Therefore, OMRDD has added “brokerage” as a fourth category to the list of essential needs for self-direction. (“Brokerage” is a term used nationally to describe a personal agent who assists a person or family in managing their budget, in hiring and training staff, and in completing documentation.) Through its federal Systems Transformation grant, OMRDD has facilitated a workgroup looking at national brokerage models that will provide recommendations on how to design this service to best support people seeking individualized choice and control. OMRDD will also develop a streamlined application process which will assist individuals to access self-determined supports in a more expedient manner.

These strategies provide evidence of OMRDD’s commitment to incorporating “individualized supports” and “self-directed services” into the fabric of the OMRDD service delivery system. OMRDD views the move toward individualized budgets and self-directed options as a way to improve quality, increase efficiency and cost-consciousness, and ultimately transform services in NYS by placing more control over resources into the hands of people with developmental disabilities and their families.



Systems Transformation – The Real Choice Grant and More

In September 2006, NYS was one of eight states selected to receive funding from the federal Centers for Medicare and Medicaid Services (CMS) in the second year of its “Real Choice Systems Change Grants for Community Living,” joining ten states which had received funding during the first round. The five-year funding award, totaling \$2.86 million, is being used to transform the long-term care system of individuals with developmental disabilities across their life spans into one which is more individualized and person-driven, enabling such persons to reside in their own homes and participate fully in community life.

Specifically, the funding is being used by three subcommittees (Choice, Funding and Housing) to advance three goals areas: (1) increase choice and control in the self-directed service delivery system; (2) create a system to more effectively manage funding for long-term supports that promote community living options; and (3) coordinate long-term supports with affordable and accessible housing. These goals will be achieved in the same collaborative and inclusive manner that has long been the hallmark of OMRDD’s service delivery system. The grant has become a major vehicle for moving much of the work related to systems change forward. Specific Strategic Plan strategies identified by the Goal Committees include:

Choice

- Increase the number, capacity and efficiency of new and existing organizations, including OMRDD, that deliver and foster individualized services across the life span, based on defined criteria.
- Conduct both internal and external public outreach about person centered design and individualized service options, with a special focus on transition periods for youth and the aging.
- Streamline documentation through the use of electronic tools and technology.
- Strengthen and promote individual and family activities within communities through volunteerism, the use of natural supports, and relationship building.
- Address the issues of recruiting and retaining a high quality workforce.
- Strengthen Quality Assurance/Quality Improvement protocols to insure emphasis on individualized outcomes and quality of life indicators.
- Make understandable information about State and voluntary providers and quality of services/supports available to all interested parties in accessible formats.

Housing

- Develop criteria for Requests For Proposals (RFPs) to non-profit and/or municipal agencies in target/pilot areas to identify barriers, existing resources and action steps for the establishment of “One Stop” access to housing with supports in accordance with intended accomplishments of RFP awardees.
- Expand existing housing policy issues group to seek greater opportunities for interagency and intra-agency cooperation.
- Develop a web-based tool to disseminate information on housing with supports.
- Develop a comprehensive marketing campaign with traditional and web-based outreach.

Funding

- Influence the ongoing cultural evolution regarding within OMRDD programs by increasing provider capacity for person centered, individualized services and supports through adequate, diverse funding across the life span.
- Increase the consistency, flexibility, responsiveness, transparency, creativity and accountability of budget development, rate setting and service billing processes in order to better support individualized design across the life span.
- Develop new and improve existing collaborative relationships among OMRDD and other agencies to integrate processes and better meet the needs of people across the life span.



Following acceptance of the Strategic Plan in 2007 by CMS, workgroups for many of these strategies were developed. The workgroups became vehicles for change that helped to energize new directions for the agency. These workgroups have now been fully integrated into the agencies' larger agenda for change. Some of the additional change activities include:

- **The Informed Choice Committee.** A definition of "informed choice" is being developed. OMRDD will consider the implications of this definition as a core outcome of its Medicaid Service Coordination (MSC) program, and relevant to the culture of all service settings.
- **The At-Home Residential Habilitation Committee.** OMRDD is developing a service option that provides individuals and families with the opportunity to co-manage At-Home Residential Habilitation (AHRH) services with the assistance of a voluntary agency. OMRDD is also working to establish an Intensive AHRH option, to address the critical need for intensive behavioral supports in the home.
- **The Business Strategies Group.** OMRDD leadership staff are defining key priorities for improving the way business is conducted, and strategies for reengineering the system.
- **The Extreme Makeover Project.** OMRDD staff across the State were invited to identify key business methodologies that are outdated or could be revised to achieve greater efficiency and effectiveness in service delivery. For example, key staff have worked together to revise the Prior Property Approval process in order to expedite the procedures related to acquiring and developing properties.

A Transformation Advisory Committee connected to the Commissioner's Advisory Council will be formed to advise the Commissioner on the many facets of work occurring across the agency. This oversight body will be charged to insure the multi-faceted activities of many committees, both within the Systems Transformation Grant and beyond, are appropriately coordinated, and consistent with the Governor's and Commissioner's priorities.

Chapter 5: People live in the home of their choice

As stated in Chapter 2, the OMRDD Vision identifies five essential outcomes for people with developmental disabilities. The present chapter focuses on the “home of choice” outcome and describes a series of activities, projects, and strategies promoted by OMRDD and its partners to increase access to a variety of living arrangements both within the family home and beyond. Some of these residential options build upon traditional approaches which emphasize formal services for several people living together in a certified setting. This model was used over the past three decades to close institutions, and successfully created a network of group homes that has served tens of thousands of individuals and families very well. This section goes on to explore other so-called “non-traditional” residential designs that provide more individualized supports, often on a less-than-round-the-clock basis. Future growth in residential supports will likely focus on expanding access to these non-certified opportunities for people who prefer them, while maintaining the traditional group home infrastructure and continuing to augment it as needs and resources dictate.

Supporting families

Supporting individuals and families to stay together as a family unit, if that is what they desire, is a core belief structure underpinning much of the planning for how OMRDD designs supports and services. Family units provide the most natural means to helping people sustain meaningful relationships, remain connected to community support systems, and integrated to community networks. In addition, supporting families to stay together is a very cost-effective way to meet the needs of people with developmental disabilities.

Over the past 24 years, Family Support Services (FSS) has grown from serving 200 families to serving approximately 42,000 families. FSS is identified in Mental Hygiene Law Section 41.43 as a family-directed, statewide system of comprehensive family support services. The purpose of family support services is to enhance a family’s ability to provide in-home care to their family members with a developmental disability. These services are absolutely vital to maximizing family strength and stability, and to supporting individuals in developing community connections and relationships through the enhancement of natural supports.

Consumer Councils are established in every Developmental Disabilities Services Office (DDSO) in order to recognize and use the knowledge and experience of families of persons with developmental disabilities, and individuals with developmental disabilities themselves, in developing NYS’s family support policies, services and supports. These Councils assist the DDSOs in the development and oversight of local FSS programs.

The Commissioner also invites family members from across the State to be a part of a Statewide Family Support Services Committee that meets on a regular basis. This Committee brings the grassroots needs of families to the attention of the Commissioner. The success of the FSS program over the years can be credited in great part to the collaboration between the Statewide Committee on Family Support





Services, local (DDSO) Consumer Councils, the DDSOs, and non-profit providers. The program's ability to be responsive to the needs and priorities of families of individuals with developmental disabilities is very much due to the continued involvement of parents and family members who are involved in the planning, implementation, oversight and evaluation of the services provided through this program.

Across the State of New York, OMRDD and its network of providers currently deliver FSS supports to individuals with developmental disabilities of all ages who live at home with their families. However, there is a need for even more support for families. In their local government plans for 2007-2009, counties were required to state outcomes that reflect desired future system improvements. Family support is one of two categories that were identified by over 50% of the counties that reported. One of the services most often requested is respite. Respite services provide temporary relief from the demands of care giving, which helps reduce stress in the home and may help to keep the family together. An allocation methodology was recently developed to expand respite services to offer opportunities to approximately 800 additional individuals in 2008-2009. In addition to respite, FSS also include programs such as: information and referral, family and individual counseling, recreation, after-school programs, transportation, and reimbursement.

Additional FSS funding was provided for in the FY 2008-09 Executive Budget. An allocation methodology was developed to distribute \$5 million in State share funding targeted to benefit up to 3,000 individuals in need of crisis intervention/behavior management support. An allocation was also developed to distribute \$2 million in State share funding for services to 1,300 individuals with autism and autism spectrum disorders. Requests for proposals will be issued to facilitate implementation.

NYS-CARES

This nationally recognized program began as a multiyear approach designed to meet the out-of-home residential needs of individuals with developmental disabilities who are waiting to move into their own homes. Its tremendous success resulted in it being codified in law, thus assuring families and individuals with developmental disabilities that the supports and services they need will be there when they need them. A second phase of the NYS-CARES program extended the commitment to providing residential, day, at-home and FSS to those in need for another 10 years; OMRDD is currently in the sixth year of this 10-year phase.

In 2007-08, a third phase of the NYS-CARES initiative (NYS-CARES III) provided support for 1,000 new residential, 200 new day and 2,500 new at-home residential opportunities over a five-year period. The NYS-CARES III initiative emphasized the development of creative residential options, such as non-traditional residences and other settings that do not require 24-hour supervision. By March 31, 2009, NYS-CARES will have provided nearly 16,500 new out-of-home residential opportunities for individuals with developmental disabilities, thus helping to meet one of the four major outcomes that are part of the agency's vision.

Self-Determined Supports and Services

OMRDD's Consolidated Supports and Services (CSS) self-directed program continues to provide two options that provide residential supports (and/or day supports) to people with disabilities and their families by allowing them to design and manage their services based on their individual needs. Under this self-directed service option, over 230 adults with developmental disabilities are already managing a personalized budget which belongs to them (i.e., is "portable") and which empowers them to hire staff and purchase needed other supports and services specified in their approved plan.

Under CSS, OMRDD has also explored two approaches used to support people who wanted to live on their own but needed additional resources, supports, and services for this to occur. The first approach allows CSS participants to share aspects of their individualized budgets so that two participants can be housemates, share room and board costs, as well as co-pay for some residential staff supports. The second approach uses a Live-in Caregiver model, and allows someone to live with the CSS participant and provide residential supports in exchange for room and board.

Although the number of people using CSS supports is still limited in relation to the number of people receiving OMRDD services system-wide, OMRDD has seen the number of CSS participants double over the last year. The success of this model has been an important advance in service design for OMRDD, proving that people with developmental disabilities, assisted by a circle of support, can manage their own individual budgets, make good



decisions, and remain safe and healthy. These findings are consistent with those of other states promoting self-direction and self-determination models. OMRDD views self-direction as a key element in its transformational agenda, and plans to simplify the application and budgeting process so that this opportunity can be made available to potentially thousands of the more than 62,000 people receiving HCBS waiver services in New York. An evaluation of the CSS service in the fall of 2007 indicated high levels of satisfaction from individuals who use this option.

Individual Support Services

Individual Support Services (ISS) were established to assist adults with developmental disabilities who want to be more independent. It provides a more flexible funding source that is designed to fit the needs of the individual. ISS can accommodate the needs of people who require a narrow range of supports to live independently and enhances choice regarding where one will live and what supports one will use.

ISS funding is available to individuals who seek to gain choice and self-direction in their living environment by moving into an uncertified, community-based residential setting. ISS funds primarily cover rent and utility costs. However, reimbursement may also include, but is not limited to: food, transportation, clothing, start-up costs, etc. There are currently 2,034 individuals enrolled in ISS statewide.

OMRDD is seeking to maximize opportunities for independent living through the use of ISS and plans to monitor ISS enrollments and spending plans on a statewide basis to determine program growth. A sample of the existing ISS budgets is currently being analyzed to develop a more responsive standardized model for providing subsidies in a timely manner. Payment structures for rental subsidies will also be reviewed to provide a more fair and equitable process.

Housing Initiatives

During the next five years, OMRDD will transform its Home of Your Own (HOYO) program to include a greater reliance on public/private partnerships to act as a catalyst to expand the supply of affordable and accessible housing for people with developmental disabilities, their income-eligible parents or legal guardians and the workforce. These public/private partnerships will serve as the catalyst to convene other grassroots and regional housing stakeholders. The partnerships will study local, regional, State and federal housing programs and policies. This will increase local understanding of the programs and policies available to assist people with disabilities to address their housing needs. The partnerships will provide training and technical assistance to non-profit organizations and act as an advocate for the expansion of affordable and accessible housing opportunities. This public/private partnership is in direct line with OMRDD's mission, vision and guiding principles – it Puts People First.

For more than a decade the HOYO program formed collaborations and partnerships within a closed enclave of State and federal housing agencies. At times, the HOYO program ventured out to meet with the private sector; however, within the past few years a concerted effort was made to bridge the divide between the public and private sectors. Time was also spent reviewing the entire spectrum of housing opportunities in NYS for people with and developmental disabilities, their families and the workforce. This new and emboldened partnership will work with diverse constituents in an effort to ensure that the supply of affordable and accessible housing meet the demand imposed by the populations supported by OMRDD. This partnership will also ensure that the populations under consideration are prepared for homeownership and have the tools necessary to keep their home.

A few highlights of the HOYO Public/Private partnerships include:

- Implementing an Asset for Independence (AFI) 4:1 Individual Development Account program in 12 counties with the assistance of local elected officials, housing and planning directors, brokerage firms, Federal Home Loan Banks, disability funds, community development funding institutions, and other groups to assist people with developmental disabilities, parents or legal guardians and direct care workers save for a down payment on their first home;
- Implementing a statewide First Home Club 4:1 matched-savings program for all OMRDD income-eligible populations, including the workforce to save for a down payment on their first home;



- Expanding the HOYO program to include direct care workers employed in State and voluntary agencies;
- Setting-up affordable housing workshops, organizing content for each workshop to best meet the needs of each local jurisdiction, and developing a format that is tailored to meet the needs of local constituents;
- Working with local officials and public and private agencies to determine the most appropriate focus for a specific jurisdiction;
- Advocating for a balance between the supply of affordable and accessible housing and demand from various stakeholders;
- Working with the private sector to establish a home maintenance and repair program for homeowners;
- Establishing a statewide financial literacy program; and
- Ensuring that people with developmental disabilities, their families, and the workforce have an opportunity to live in affordable, accessible, safe, secure, and stable housing.

New York City Resource Consortium

OMRDD continues to promote individual choice in services and supports, which has increased the demand for smaller, more individualized living arrangements. Beginning July 1, 2008 OMRDD initiated a partnership with the Developmental Disabilities Planning Council (DDPC) to establish and support a New York City (NYC) Resource Consortium for a two year period. Four voluntary agencies, AHRC NYC, Cerebral Palsy Association of NYS, HeartShare Human Services, and Sinergia, Inc., were selected via a Request for Proposals process. The Consortium agencies have been working with OMRDD, DDPC, DDSOs, the NYC Department of Health and Mental Hygiene (NYC DOHMH), and NYS Division of Housing & Community Renewal (DHCR) to provide leadership in NYC to promote access to small individualized living environments for people with a wide range of ability and support needs. It is expected that the NYC Resource Consortium will lead the way in designing innovations and best practices to facilitate the availability of these living arrangements to meet the growing demand from the people OMRDD serves.

During Year 1, each Consortium agency identified and convened its own agency resource workgroup, including one or more persons with developmental disabilities who are employed as interns and mentored by the agency as part of OMRDD's Employment Training Program (ETP). The agencies are providing the interns with opportunities for meaningful work experiences and future long-term employment after proving themselves to be responsible and productive employees during their internship periods. Each Consortium agency has also identified 10 or more eligible individuals; and using the most appropriate funding sources, began to plan for their moves during Year 2 into small individualized living environments of his or her choice; or be maintained in their current living arrangement with enhanced supports.

Throughout the two year period, the NYC Resource Consortium will collectively work with OMRDD to develop and disseminate information, and provide training and technical assistance to NYC agencies, self-advocates, people with disabilities and their families/advocates regarding the range of options and how to realize the best possible home environment. The agencies will also compile their best practices and success stories to disseminate throughout the NYC region to sustain the initiative beyond the two year period.

Shared Living

Many of OMRDD's efforts support people with developmental disabilities living, working, and recreating in their communities, alongside their neighbors. If our service system is truly dedicated to supporting people with developmental disabilities to live in the "right" home of their choice, we need to look towards the use of more non-certified residential settings. Many people being served today in certified residential sites have expressed their desire to live with their family members or in their own homes/apartments with an appropriate level of supports. Additionally, many young adults transitioning from the school system are not looking for certified residential options, but are seeking apartments they can share with their friends. Often it is difficult for a young adult to pay for an apartment on their own. In many areas of the State this is also cost prohibitive, even for young adults who are not disabled. Therefore, OMRDD must explore various models that support "shared living" approaches for people with disabilities. These models may include ways to share room and board costs, as well as co-sharing staff supports. Companionship and Live-in Caregiver Models will be further explored and enhanced.



OMRDD plans to identify other shared living arrangements that can be supported for individuals, and work with the NYS Department of Labor to develop guidelines and solutions that will allow people with developmental disabilities to live in their communities, with staff of their choosing that will also be in accordance with Fair Labor Standards, Workers Compensation, and other NYS Labor Laws and Regulations, as well as adherence to State and Federal Medicaid Regulations.

OMRDD will continue to participate in a statewide workgroup, comprised of individuals with disabilities, parents, siblings, and other family members, providers, and policy makers, to define shared living arrangements that will support people with disabilities effectively. Regional forums will be held to gather information on exactly what living arrangements people are seeking. OMRDD will also take a major lead in designing residential approaches that will increase the number of shared living opportunities available statewide.

Family Care

OMRDD's Family Care (FC) program is in the vanguard of options for persons who seek personal growth through individualized opportunities. FC providers open their homes to individuals to help them achieve their personal goals.

With a successful history as a stable program resulting in a current enrollment of 2,700 individuals in 1,466 homes statewide, FC is poised for a larger role in person centered choice. With the support of the Commissioner and in conjunction with the Commissioner's Advisory Council on FC, new ideas to further invigorate this program are being discussed. Current issues facing FC include the aging of providers and the individuals in the home, as well as the availability of respite options.

Key stakeholders from each DDSO will play an integral part in the implementation and promotion of new ideas through the creation of more personalized opportunities, provision of training, and other innovative benefits for the FC provider and the individuals in their homes. The expectation is that by building on the sound basis that is FC today and applying this renewed focus, FC will be offered more broadly as an option of choice for individuals and their families.

Children Residing Out-of-State

Billy's Law, passed in 2005, seeks to return children who are placed into private residential schools outside of NYS, and to create the in-State infrastructure sufficient to accommodate the future needs of children. According to a July 2008 estimate there are 786 children who remain in out-of-State private residential schools. This number represents a reduction from the number of 1,200 children living out-of-State at the time that Billy's Law passed. The law established the out-of-State placement committee which then created several workgroups to analyze and report back to the committee on various aspects of this issue: infrastructure, model process, contract development, and a registry of schools. OMRDD continues to work with various State agencies, primarily the State Education Department (SED) and the Office of Children and Family Services (OCFS), on aspects of these issues.

In response to the passage of this law, NYS undertook the multi-agency initiative of developing needed infrastructure. Several OMRDD/SED joint projects create new in-State opportunities for children with developmental disabilities while another group of similar OCFS/SED joint projects will be developed for children with other disabilities.

With the goal of developing sufficient in-State residential alternatives, the out-of-State placement committee continues to work collaboratively with other child serving State agencies on analysis of needs and to amend the in-State development plan appropriately.

Nursing Home Diversion

As a policy position, OMRDD seeks to enable individuals to live out their lives supported in their homes, remaining as engaged in their relationships and communities as possible. As is the case with most people, nursing home admission for a person with a developmental disability is viewed as a last resort, only to be pursued when being supported in the community is no longer practicable. OMRDD is fully compliant with the federally mandated Pre-Admission Screening and Resident Review (PASRR) process for individuals with developmental disabilities for whom nursing home services are sought. As such, individuals eligible for OMRDD services are



identified prior to nursing home admission. In this process, every effort is made to ensure that services and supports to enable the individual to remain in the community are researched and found unavailable or inappropriate. Unnecessary nursing home admissions prevented in this manner are tracked and reported within the agency's monitoring of internal controls.

Nursing home diversion is also a priority of the Department of Health (DOH). OMRDD fully supports these efforts, lending staff time and expertise to the development of both its Nursing Home Transition and Diversion waiver and Money Follows the Person federal demonstration applications and implementation. Individuals with developmental disabilities are among the target groups to benefit from for these initiatives.

Developmental Center Services

The heart of OMRDD's mission is to provide individuals access to needed supports and services, including a home in the community. The 2008-09 budget provided opportunities to develop community living arrangements for people now living in institutional settings, which will result in institutional downsizing and redefining of OMRDD's institutional capacity. OMRDD's institutional capacity is comprised of both the remaining small developmental center capacity and a number of specialized units.

As the first step in a multi-year plan to downsize and potentially close developmental centers, OMRDD initiated the transition of most individuals residing in the Western NY Developmental Center to community living. This transition will occur over several years; will allow nearly 80 people to live in a more integrated and person centered setting in the community; and will result in closure of this campus. The downsizing and potential closure of the remaining developmental centers, where over 400 individuals currently live, will also begin in 2008-09, using homes operated by both the State and non-profit providers.

The Community Placement Process (CPP), implemented September 1, 2007, creates a standard set of guidelines and principles that synthesizes and integrates current DDSO practices for planning and development of appropriate community living arrangements. Understanding that each district will retain elements unique to local operations, the CPP outlines certain values and expectations for person centered approaches, considers individual and family member preferences, describes district planning efforts, and tracks and monitors progress to ensure consistency on a statewide basis.

Person centered planning for people leaving institutional settings must address all needed supports and services in the community, identify potential providers of service and delineate responsible parties for the plan's implementation. While the responsibility for tracking and monitoring each plan's progress will continue on a local level, OMRDD's current Tracking and Billing System will have an enhanced capacity to allow for monitoring and tracking centrally.

In addition, the 2008-09 budget supported the development of residential opportunities in the community for people living in other institutional settings, such as nursing homes and OMRDD specialized behavioral units, and those who are dually diagnosed with mental illness and have a developmental disability. These resources help individuals with developmental disabilities who also have high medical needs or challenging behaviors achieve the greater independence and choice that comes with living in the community.

In redefining institutional capacity and transitioning individuals into community settings, OMRDD remains committed to the staff who provide services to them. This not only assures continuity of the relationships that have been developed, which is so important for all people including individuals who have developmental disabilities, but also assures continuity of employment for OMRDD's valued workforce.

OMRDD recognizes the need to provide specialized services to a limited number of individuals in more structured settings until they can be appropriately served in the community. Maintaining quality services in institutional settings is critical to maximizing opportunities for people to develop the skills they will need to successfully transition to the community and live in the home of their choice. Technical Assistance is an integral part of maintaining and improving the quality of services afforded individuals in institutional settings, and the inclusion of clinical staff on Technical Assistance teams provides an opportunity to improve services through on-site consultation and training. It is essential that clinicians stay abreast of the ever-increasing best practices literature in the field. OMRDD needs to insure the dissemination of information that can enhance the quality and excellence of services. To facilitate this outcome, OMRDD will:



- Create and deliver trainings on regulatory requirements and best practices recommendations for Functional Analyses of Behavior and Behavior Support Plans to providers requesting assistance;
- Continue to provide support, consultation, and recommendations to OMRDD institutional settings as adjunctive members of the Technical Assistance Team; and
- Survey Psychology staff at OMRDD institutional settings, CQCAPD, and Quality Management staff to determine which clinical issues would best be targeted in future consultations and trainings.

Home and Community Based Services Waiver

OMRDD has continued to offer people the opportunity to live in the home of their choice with the services and supports that they desire through its Home and Community Based Services (HCBS) waiver. The HCBS waiver offers individuals and their families a flexible choice of residential options. Through the waiver, OMRDD accomplishes its commitment to provide individualized and person centered services to all participants.

With an increased focus on supporting person centered options, individuals can choose to live in homes that meet their specific needs. The HCBS waiver services of Residential Habilitation in certified settings, FC, at-home and Consolidated Supports and Services (CSS) allows individuals to receive the supports and services needed to live in the home of their choice. Other Waiver services such as Respite, Environmental Modifications, Adaptive Devices, and Family Education and Training (FET) support individuals at home independently or with their families.

OMRDD is working on a new programmatic and fiscal platform for the delivery of At Home Residential Habilitation (AHRH) services. Programmatically, OMRDD is working with providers, self advocates and families to develop a service option that provides individuals and families with the opportunity to co-manage AHRH services with the assistance of a voluntary agency. OMRDD is also working to establish an Intensive AHRH option, to address the critical need for intensive behavioral supports in the home.

Recently, OMRDD expanded its HCBS waiver respite services to include 800 additional individuals. Waiver respite provides a relief for caregivers of individuals with developmental disabilities by providing respite in a setting of their choice.

Through the use of waiver Environmental Modifications and Adaptive Devices, individuals are utilizing more creative and innovative technology to ensure their independence and safety at home. Through its waiver, OMRDD will continue to explore the use of “smart homes” to develop technological adaptations to individuals own homes in order to provide more freedom and independence in the future.

The use of the waiver service of FET allows more and more parents of children with developmental disabilities to receive needed training and education regarding their child’s disability.

Outcomes and Performance Measures

The following outcomes and performance measures have been developed to define the key focus areas for work activities related to supporting people to live in the home of their choice.

Outcome:

OMRDD will support individuals with developmental disabilities to live at-home with their families when this is the preferred choice of the person and his or her family.

Performance Measure:

- Increase in the number of individuals supported by families that access family support services.
- Increase in the number of individuals receiving at-home and intensive at-home habilitation services.
- Increase in the number of HCBS waiver respite services utilized.

Outcome:

Expand residential, day and at-home opportunities over the next five years through NYS-CARES III.

Performance Measure:

- Increase in the number of people accessing individualized, non-certified living arrangements, including those using services such as Individual Support Services (ISS) and self-directed options.
- Increase in the number of people accessing out-of-home residential opportunities through NYS-CARES.
- Increase in the number of people receiving day service opportunities through NYS-CARES.

Outcome:

Expand the opportunity for people with developmental disabilities and their families to direct their own services and supports.

Performance Measure:

- Increase in the number of people accessing self-directed supports and services.

Outcome:

Revitalize and promote Family Care as a viable residential option for people who want to live as part of a family environment.

Performance Measure:

- Increase in the number of family care homes.
- Increase in the number of individuals in family care services.

Outcome:

Provide for the needs of children safely and in the least restrictive, most integrated setting.

Performance Measure:

- Decrease in the number of identified children with developmental disabilities in out-of-State placements.
- Increase in the number of children's residential opportunities in NYS.

Outcome:

Individuals with developmental disabilities will not be admitted to nursing facilities unnecessarily, and individuals living in nursing homes will be enabled to return to the most integrated and appropriate community residential setting of their choice.

Performance Measure:

- Decrease in the number of individuals who are eligible for OMRDD services and reside in nursing facilities, and are requesting to move to a less restrictive setting.

Outcome:

Prepare more people living in developmental center and special population units for community living.

Performance Measure:

- Increase in the number of individuals transitioned to community-based settings who were living in developmental center and special population units.

Chapter 6: People work and fully participate in their communities

The opportunity to work and/or participate in meaningful community activities is another key outcome cited in OMRDD's Vision Statement. A life of paid employment is the expectation for typical adults in our society, and is a defining element in how we view ourselves and judge our value. That opportunity must be made available to all citizens regardless of their need for support to achieve that goal. People with developmental disabilities bring an abundance of gifts and talents to their communities, and we are a lesser society by far if we do not welcome their contributions to our neighborhoods, organizations, and businesses. Over the past three decades, people with developmental disabilities have demonstrated that they are capable, reliable, and productive employees and some have entered the entrepreneurial ranks by operating their own businesses. They want to work and be self-sufficient, and their capacity for creativity and contribution is unlimited. This section describes several initiatives designed to assist people with developmental disabilities to work and to participate in community life in other ways, through volunteering and membership, so that our workplaces and neighborhoods truly reflect who we are as a society.



Employment

OMRDD is promoting Employment First as a preferred outcome for persons with developmental disabilities who choose to work. By choosing to work and achieving the personal, social, and monetary benefits that accrue to all individuals who are employed, individuals with developmental disabilities will experience the dignity of self-worth of being valued employees, financial freedom and fully engage in their communities.

OMRDD is piloting a new strategy for assisting people to achieve their employment goals called "Enhanced Supported Employment" through a Request For Proposals (RFP). The pilot will support at least 700 new people in employment for a five year period. This pilot, along with other strategies, is designed to promote an Employment First agenda which will serve as the basis for assessing what new approaches can be developed that assist people with developmental disabilities to achieve their employment outcomes. Information provided from the evaluation of the pilot will assist OMRDD to evaluate the effectiveness of the supports provided through this pilot in achieving this outcome and the development of future policy. OMRDD has included transportation for work as a possible service in this pilot. Transportation is a major barrier to employment and OMRDD will evaluate how the service is utilized as part of the pilot.

The Employment Training Internship program enables employers to employ individuals with developmental disabilities and have their wages paid by OMRDD for a period of up to 18 months. The internships are paid by OMRDD in an effort to provide expanded employment opportunities that will lead to long-term employment in the private sector, governmental agencies and non-profit organizations. In 2007/08 more than 130 self-advocates and individuals with developmental disabilities were in internships. In 2008/09, OMRDD expects that an additional 128 interns will participate. As of August 2008 an internship program has been established at every Developmental Disabilities Services Office (DDSO), thereby

offering an individualized employment opportunity to OMRDD individuals statewide. OMRDD hopes to expand the capacity of OMRDD Internship Program to assist individuals who may need a long-term on the job training experience in order to be successfully employed. OMRDD will also seek to explore new ideas for internships with business and industry leaders.

OMRDD will provide training on work incentive programs to all of the stakeholders who support individuals in gaining and sustaining employment (including individuals and their families) so as to dispel myths around the impact of employment upon benefits. Training for service coordinators will be developed which promotes Employment First! The training will frame the Employment First vision, answer questions, and provide a basic introduction to the work incentive programs that enable individuals with disabilities to maintain their health insurance and other benefits while they are working.

In order to ensure that individuals with developmental disabilities have the best possible employment outcomes, it is important that the workforce of job coaches and job developers are well trained and supported in a manner consistent with their responsibilities. OMRDD in partnership with the State supported employment partner agencies, the Association for Persons in Supported Employment (APSE), and the provider associations need to explore how to provide better training and benefits for employment support staff.

In order to promote our workforce, OMRDD will explore new strategies to assist people to be successful workers in emerging industries and sectors of the economy. Some of the strategies will include identifying emerging sectors in our various regions, and then working with our DDSOs to explore with community partners how our individuals can become trained and ready to work in these sector industries. OMRDD wants to move the workforce into emerging sectors, and let go of jobs that are becoming outdated and have no future. As a component of this theme, it is possible that OMRDD may want to explore the idea of sector based training programs which are developed for people with developmental disabilities.

Other strategies for marketing our workforce include:

- Development of a marketing video which demonstrates the jobs of distinction of people with developmental disabilities. The video can be used with employers, businesses, and trade associations to demonstrate the capacities of our workforce.
- Development of a marketing packet which highlights the strengths of our workforce and provides tax incentives and other promotional information to businesses.

Most Integrated Setting Coordinating Council. The Most Integrated Setting Coordinating Council (MISCC) is a statutorily created council that is developing and implementing a plan to ensure that all people with disabilities receive services and supports appropriate to their needs in the most integrated setting. The Employment Committee of the MISCC will be making recommendations to the MISCC concerning strategies that are designed to promote employment for workers with disabilities and to significantly increase the number of workers with disabilities in the State of New York.

OMRDD is a full participant on the MISCC employment group and is committed to promoting the employment themes for all individuals with disabilities including the interests of people with developmental disabilities. The five themes that are being developed as recommendations to the MISCC are:

1. Public sector employment;
2. “No Wrong Door” service delivery;
3. Marketing the Work Incentives Programs and the Medicaid Buy In;
4. Data and funding integration; and
5. Marketing to employers.

Each of these themes will impact the ability of people with developmental disabilities to be employed and fully participate in their communities.

Transition Planning

The transition of children to adult services is an important milestone that requires careful planning. In an attempt to augment the planning already required to be done by school districts, OMRDD participates in meetings with the State Education Department (SED) regional transition coordinators to enhance the possibilities for smoother transition and insure that students are connected to sufficient and appropriate adult services.

OMRDD plans to partner with SED on the planning for career exploration, job coaching and other strategies for transition aged youth that promotes the philosophy of Employment First. OMRDD is also working with SED to develop collaborative opportunities for improved provision of services designed to prepare students for employment while they are in school.

Blended Services/HCBS

Starting in winter 2005, OMRDD awarded the first blended day services (planned use of different HCBS waiver day service options for the same individual) using a pilot contract mechanism that is set up for a five year period. The caveat to any contract award was that a provider must ensure all services outlined in their pilot proposal, such as blended day habilitation and supported employment services, must provide to all targeted individuals components of each distinct service outlined in the blend. Each person who participates in the blended service has a habilitation plan that describes the supports and services associated with each distinct service component. For each service day, staff document services that are drawn from the habilitation plan and the provider's reporting for payment purposes reflect which service components were provided on that day (e.g., only day habilitation or a combination of day habilitation and supported employment).

In order to ensure compliance to this rule, along with regular program monitoring, the OMRDD does an initial desk review for each provider after the first contract billing for blended services. Allowed services include combinations of traditional day services using Medicaid guidelines from the OMRDD HCBS waiver.

To date, OMRDD has approved approximately 50 proposals for blended services. Anecdotally, OMRDD has heard that individuals participating in these services are pleased with the ability to receive services according to a plan that allows for greater flexibility in their day or week. Providers report that though they have to keep separate notations for each service, they have greater flexibility in designing program services based on individual desires without worrying about whether they have met an individual billing standard for one particular service on a given day.

Through the creative exploration and use of waiver services combined, individuals are able to fully participate in their communities. The blending of services has allowed individuals opportunities for engaging in meaningful employment while continuing to receive needed supports, such as day habilitation or pre-vocational skills. Additionally, some individuals may opt to participate in continued day habilitation services if they are not employed full-time. This flexibility has allowed OMRDD to provide more individuals with innovative opportunities of individualized services that meet their needs in their own communities, while preserving the distinct identification of each waiver service within the person's plan of services (ISP).

Volunteerism

OMRDD is developing an employment and volunteering guide for use by the DDSOs. The overview will provide regulatory and service option information which can help to guide the development of employment (including self-employment) career exploration and volunteering for individuals with developmental disabilities who wish to pursue these options. This overview is intended to provide the DDSOs with a better understanding of the pertinent regulations which apply to volunteering and employment. It is often a lack of clarity around regulation and policy that inhibits creative solutions that could increase volunteerism and employment.

Fostering Community Acceptance

OMRDD has come to recognize that a large part of what needs to be done to accomplish the objectives of the Community Participation initiative stems around how to change the expectations and views of community members, as a whole, about people with developmental disabilities, and the gifts and talents they have to share. Traditionally, OMRDD's focus with promoting community participation has traditionally been one-sided. We have often focused only on the person with a disability by asking them "do you have enough opportunities to be a



part of your community” or “are you getting out enough.” People must also look towards the community itself and seek to determine how best to have an impact on changing the views and expectations of the community about people with disabilities and the contributions they make to their community. Increased efforts will be undertaken to use various media to educate communities at large about people with disabilities that will showcase their successes in fostering friendships, successful community involvement, and full participation through work, volunteerism, and recreation. Successful practices will be shared and replicated throughout the State; not just within the OMRDD service system, but with family members, provider associations, community neighbors, employers, policy makers, and others.

Outcomes and Performance Measures

The following outcomes and performance measures have been developed to define the key focus areas for work activities related to supporting people to work and fully participate in their communities.

Outcome:

Individuals with developmental disabilities will become meaningfully employed in preferred job situations and sustain their employment for significant periods of time.

Performance Measure:

- Increase in the number of individuals employed.
- Increase in the number of individuals who choose where they work.
- Increase in the number of individuals who maintain jobs for one year or longer.

Outcome:

Individuals with developmental disabilities, as part of the transition process, will learn about the various career and employment opportunities, and ultimately have the supports necessary to access employment after graduation if that is their preferred option.

Performance Measures:

- Increase the number of young adults who transition directly from high school into employment.
- Decrease the number of young adults who access full time day habilitation services, instead of employment, upon leaving school.

Outcome:

Individuals with developmental disabilities will receive the employment and day supports needed to become employed in the jobs of their choice and/or contribute to their communities in meaningful volunteer roles.

Performance Measure:

- Increase in the number of individuals who volunteer in the community.
- Increase in the number of individuals who receive blended supports.

Outcome:

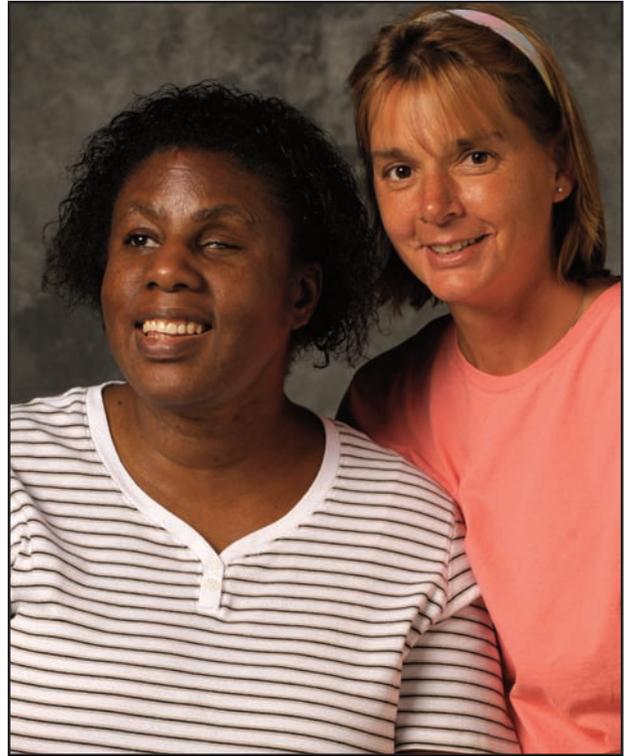
State agencies, including OMRDD, will be involved in the transition of students to adult services so that more children are connected with opportunities to participate in their community as adults.

Performance Measure:

- Development of a process to share data between schools and adult service agencies to improve transition planning.
- Creation of a release/referral form to share personal data with agencies that support adults.

Chapter 7: People enjoy meaningful relationships with friends, family and others in their lives

Human beings are social beings. We are built to connect to others – family, friends, neighbors – in a variety of ways, and these connections are essential if we are to grow, learn, work, play, remain safe, and reach our full potential. One of the sad legacies of earlier models of care for people with developmental disabilities was their reinforcement of stigmatization and segregation in impersonal institutional settings, dynamics we are still struggling to overcome as a system and society. So many of our core values – compassion, dignity, diversity, honesty – have as a basis the interpersonal side of our nature. They only make sense in the context of our interactions with one another. If we are to succeed in supporting people with developmental disabilities to “lead richer lives,” we must put an end to isolation, combat loneliness, and emphasize the development of social networks and personally satisfying reciprocal relationships for all people.



Community Inclusion

As OMRDD works toward achieving its mission, “to help people lead richer lives,” the agency makes a commitment to assist people for a lifetime, to build community membership over time through participation in a variety of day-to-day activities. The level of participation must be based on each individual’s capacities, needs and preferences, and supported by family, friends, neighbors, volunteers, community organizations, and staff. A self-advocate wisely advised Commissioner Diana Jones Ritter that what she wanted was “a life,” something everyone wants, and not just “presence” in the community. The advocate stated a wish for meaningful participation based on her individual needs and not a predetermined standard. She also wanted “choice,” so that she would be able to decide what she would like to do, when she would like to do it, and with whom. And she desired to be valued, so her contributions were recognized and she could help improve her own life and the lives of others. OMRDD has enhanced its website to profile people who are living their lives, and will add functional information to help individuals, their families and providers know what inclusion is and how best to achieve it in a person centered way.

Family Support Services (FSS) also provides opportunities for individuals with developmental disabilities to enjoy relationships both with their families and with friends and other members of their community. These opportunities are provided through services such as respite, after-school programs, camps, recreation, and transportation.

Building Relationships with Staff

Research in developmental disabilities is clear that the best way to both prevent abuse and promote richer lives is to strengthen value and nourish the relationships between individuals with developmental disabilities and those that care for them. In OMRDD’s



case, this includes the more than 90,000 staff in state and voluntary programs. Conversely, when an individual is abused by staff several negative things happen. In addition to the actual physical or psychological impact on the person who has a disability and the penalties to responsible staff, there is another pervasive impact which may be even more devastating. In the abusive act the very essence of the helping relationship is destroyed. Abuse harms more than the person with a disability and more than the staff; it harms the relationship, and thereby harms the shared trust, which is needed for people to thrive.

Research has also found that events of abuse, neglect or serious incidents are often directly related to the stressful work and work environment of otherwise committed, hardworking and dedicated workers. Further, the emotional, familial, financial, and other stresses that many of our direct care workers are facing more broadly in their lives can have a direct impact on their ability to deal with such workplace stresses, and therefore their capacity to react in ways that avoid abuse, neglect or serious incidents.

In June 2008, Commissioner Ritter announced a three-pronged initiative to reduce the frequency of abuse, neglect and serious incidents in New York's system of services and supports for people with developmental disabilities. With the support of the School of Social Welfare at the University at Albany, OMRDD is creating a prototype at the Capital District DDSO that, over the next two years, will be rolled out through the entire public and private system.

The goals of the initiative are to:

- Develop a shared concrete understanding of, and commitment to promoting positive relationships between staff and the people they support;
- Equip staff with essential competencies to nurture and develop these relationships;
- Engage staff in identifying issues within the work environment, both physical as well as procedural, that either obstruct opportunities to nourish those relationships or actually contribute to the stresses that undermine them; and
- Develop reasonable, sustainable responses to these issues.

Everyday Heroes

OMRDD's *Everyday Heroes* initiative began in 2001 in NYC, when direct support professionals from voluntary agencies and DDSOs helped design a "How To" curriculum and companion teaching materials to aid direct support professionals in their work efforts that help support community lives for people with developmental disabilities. The workbook, storybooks, and annual calendars developed through the years share the *Everyday Heroes* values system wide, and collectively teach the values of inclusion from a direct care perspective. The Developmental Disabilities Planning Council (DDPC), the Civil Service Employees Association (CSEA), and Westchester ARC partnered with OMRDD to produce the *Everyday Heroes* Instructional DVD and *Users Guide*, which has been disseminated widely throughout NYS, the nation, and even Australia. The DDPC has funded ten agencies to incorporate *Everyday Heroes* values within their organizations, implement best practices for inclusion by their direct support professionals, and then mentor other agencies on *Everyday Heroes*.

Everyday Heroes is more than a training curriculum -- it is a mindset nurtured by OMRDD. *Everyday Heroes* are the direct support professionals who help people with disabilities make community connections everyday. The relationships the staff have with the people they support are key to building these community connections. Staff support people with developmental disabilities to deepen relationships with friends, family and neighbors: "they nurture relationships with community members; they listen to people with their hearts and see into their souls; and they build alliances with families and advocates." *Everyday Heroes* are found throughout the DDSOs and voluntary agencies. Their stories detail the unique strategies for inclusion that come from the collective imaginations of direct support workers, administrators, and clinicians -- how and why life changed, and how people moved from old ways, to better and ultimately best practices in community inclusion. *Everyday Heroes* demonstrate that the "ultimate best" is evidenced by the impact people with disabilities, staff, and community members make on their communities, working together. Some of these stories can be found on the home page of the OMRDD web site. OMRDD will continue to promote and support activities related to implementation of the *Everyday Heroes* curriculum.

Community Participation Initiatives

OMRDD's existing Community Participation Workgroup reconvened under OMRDD's federal systems change initiative. Workgroup objectives are to identify and promote efforts to increase community experiences for all citizens of NYS including those with developmental disabilities. The Community Participation Workgroup reviewed the 2007-2008 Community Participation action plans generated by each DDSO, the Self Advocacy Association of New York

State, and OMRDD Central Office. Concerted efforts were made to increase in the participation of self-advocates and generic community representatives in all aspect of systems design.

The Community Participation Workgroup identified the following elements as necessary for the expansion of community experiences for people served by OMRDD and its network of providers. Consequently, each district plan will be reviewed to identify:

- activities that create and support more individualized opportunities for community participation for people with developmental disabilities;
- activities that promote vision, leadership, and a greater awareness of community participation for individuals with developmental disabilities, family members, the community at large (including potential employers), and/or providers and provider associations; and,
- strategies built into local action plans that increase community participation for people with developmental disabilities into the future on an on-going basis, rather than the promotion of one-time events.

With assistance from evaluators, OMRDD will assess the effectiveness of the various activities identified within each DDSO action plan. Several DDSO regions will be profiled for their exemplary practices in promoting community acceptance, community involvement, and full participation. These practices will be replicated in other regions of the state.

In order for OMRDD to advance the vision of community participation for all people, it must embrace new service designs which specifically promote participatory outcomes, and which honor the choices people make to participate in their communities in their own way. New options for individualized supports include Consolidated Supports and Services (CSS) and Agency-With-Choice (AWC). Making these options more universally available will require the infrastructure support of the DDSOs, in conjunction with their regional planning groups. The DDSOs will develop 2008-2010 local Community Participation Action Plans which will continue to identify goals that promote the development of individualized supports and choices.

Faith-Based Initiative

The OMRDD Faith-Based Initiative was instituted by Commissioner Ritter in May 2007. Its mission is to explore new avenues and expand opportunities for individuals with developmental disabilities to express their beliefs, support their right to belong to a faith community, and assist them to become a valued member in their chosen house of faith.

The first step toward meeting the goal of supporting individuals in their faith choice and expectations was to survey the DDSOs. The purpose of these surveys was to determine the DDSOs' current status with respect to including faith community inclusion in person centered planning for the individuals they serve. The following groups were surveyed: individuals with developmental disabilities in OMRDD's care, DDSO administration, DDSO chaplains, house and unit staff, Medicaid service coordinators, active treatment coordinators, and family care providers. These surveys were recently completed. Based upon analysis of the survey information, strategies for reaching out to the faith community and building support systems for integration will be instituted.

Survey results indicate that the major concerns of individuals with developmental disabilities who have expressed a faith choice are: (1) the lack of transportation to community faith worship and activities, (2) the lack of staff to assist them with access to their house of worship, (3) the need for education and training of staff to increase staff comfort with their participation in community worship, and (4) the need for outreach and dialogue with congregants to increase their comfort with the presence of individuals with developmental disabilities. These surveys also indicated that individuals with developmental disabilities would like more opportunities to participate in other forms of faith worship, such as faith community social gatherings and music programs. They

also expressed concern about being able to find a place where they can share in the faith community experience.

Within the next five years OMRDD plans to make significant inroads with respect to partnering with the faith community, and other interested parties, to build support systems that will sustain an individual's inclusion in his or her chosen faith community. This will involve connecting with regional support systems as resources for faith community inclusion, establishing stronger partnerships between OMRDD's DDSOs and community faith leaders, and developing education and training resources for stakeholders of faith community inclusion. OMRDD plans to institute policies, and collect data on performance metrics, to insure opportunity and support for faith community inclusion. A database of houses of worship (including accessibility) will be created which will be located on the OMRDD website to assist individuals and the people who support them to identify faith based opportunities in their community.

Outcomes and Performance Measures

The following outcomes and performance measures have been developed to define the key focus areas for work activities related to supporting people to have meaningful relationships with friends, family and others in their lives.

Outcome:

Individuals with developmental disabilities will have more opportunities to participate in community activities of their choosing, and enjoy meaningful relationships in their lives.

Performance Measures:

- Increase in the number of training opportunities for direct care staff on how to support individuals' desires for community participation.
- Increase in the number of information-sharing and training opportunities available to a variety of community groups in order to enhance acceptance of people with developmental disabilities through meaningful participation in their communities.
- Increase in the percentage of favorable responses to National Core Indicators (NCI) Consumer Survey community inclusion indicators.

Outcome:

Individuals with developmental disabilities will have more opportunities to enjoy meaningful relationships in their lives.

Performance Measure:

- Increase in the percentage of favorable responses to NCI Consumer Survey relationship indicators.

Outcome:

Individuals with developmental disabilities will participate in and be a part of the faith community of their choice.

Performance Measure:

- Increase in the number of individuals participating in faith-based activities / worship in the community.

Chapter 8: People experience personal health and growth

The fifth cornerstone of OMRDD's Vision Statement is to help the individuals we serve to achieve or maintain good health. Indeed, this is a foundational element to help individuals exercise greater autonomy, choice and control in all other aspects of their life. OMRDD is exploring strategies to transform the way we conceptualize and deliver medical/health, behavioral, clinical and nutrition services to assure that individuals are supported to achieve their maximum potential in the most integrated settings possible. OMRDD is also examining and developing strategies to assure that clinicians are highly trained and qualified to deliver behavioral and clinical services to the individuals who require these supports at all levels of care. This section describes several initiatives designed to positively impact the health and wellness of the individuals we support as well as increasing the quality of those behavioral and clinical supports.



Smoking Cessation

One of OMRDD's goals is to identify and encourage excellence in supporting individuals with developmental disabilities. This involves the continual emphasis on innovation, increasing knowledge, finding and promoting best practices, and delivering the highest quality supports and services. With this in mind, OMRDD is promoting "tobacco free" environments and lifestyle changes for both its customers and staff.

Upwards of five million people die worldwide every year from tobacco use. In the past, a number of our customers and staff have been a part of those tragic statistics. As part of an overall wellness initiative, OMRDD is committed to providing guidance and support on the best ways to quit using tobacco and on creating tobacco free environments.

OMRDD will make available to people with developmental disabilities and staff tobacco dependence education, in which they will be provided with the resources they need to learn about the health concerns and risks of tobacco use. Education and training will include strategies to assist people in their efforts to become tobacco free. In addition, OMRDD will supply people with developmental disabilities with nicotine replacement products and other supports as necessary so that they will be successful in their effort to quit smoking.

Medical Immobilization/Protective Stabilization

Good health is essential to the quality of life. The United States Health Services states that, "routine preventive services, from periodic oral prophylaxis and restoration, to cancer screening, immunizations, and early intervention with emerging mental illness are critical to prevention of more serious conditions and secondary disability." Consequences of inadequate health care can mean pain for the individual, poor nutrition, infection, and chronic illness

Some factors that may interfere with a person's ability to obtain good health care can include; involuntary, limited, or resistive movements; limited ability to control movements; difficulty with body positioning; fear; limited communication capacities;

increased sensitivity to touch, lights, sounds, and smells; and a previous negative experience.

In order to successfully receive needed medical treatment, dental treatment or x-rays, individuals with developmental disabilities sometimes need supports. This can include the use of Medical Immobilization, Protective Stabilization (MIPS) and/or sedation. These interventions, when appropriately used, can facilitate comfort and cooperation, protect the health and safety of the individual and others, prevent injury, and facilitate delivery of quality health care. Additionally, several DDSOs have taken advantage of the portable x-ray demonstration program, recently extended for another two year period by Chapter 149 of the Laws of 2008, which is administered by the Department of Health, and is particularly beneficial for those individuals who are medically fragile.

Trained direct support staff who accompany individuals to medical and dental appointments can play an important role in assisting the health care professional to achieve a successful outcome for the individual.

Telemedicine

The purpose of the Telemedicine system is to prevent or reduce unnecessary, stressful and time-consuming emergency room visits. Usage is limited to connecting a remote site to a triage nurse via a computer and video monitor. This allows for better use of nursing resources while improving quality of life while reducing Medicaid costs.

There are seven providers in the Finger Lakes region that are using a Telemedicine system to help deal with health issues at residential and or day program sites. One system is funded by OMRDD, while the others are funded by the Golisano Foundation. The OMRDD funded system is used at an Individualized Residential Alternative (IRA) that serves individuals who are elderly with numerous health issues.

There are two types of systems available, one is called "Tel-e-Atrics-Connect" system and the other is a Tele-monitoring system. The Tele-e-Atrics system used by an OMRDD provider has helped facilitate over 40 visits since it was installed. It has resulted in the avoidance of a hospital visit in one occurrence. This system uses a computer with a video monitor hook-up with various attachments. The second system, a Tele-monitoring system, has been used by the same provider with a less medically frail, but more independent group of people. Staff report they are able to monitor individuals more frequently, resulting in fewer on-site visits to the three residences where it is installed. The Tele-monitoring system collects basic health data on individuals on a predetermined basis, and allows clinical staff to establish a person-specific health baseline or monitor status after a significant health event.

It should be noted that the one provider using both systems believes that both systems are really more appropriate with a less medically frail population. When a medically involved individual goes into distress, users report there is little time to set the system up to evaluate the situation. Action needs to be taken immediately. However, the provider is very pleased with outcomes thus far and will continue to test both systems.

Osteoporosis

Osteoporosis is a bone disease that increases the risk of fractures. According to the National Health and Nutrition Examination Study, osteoporosis affects more than 10 million people in America over the age of 50. People with disabilities are often affected at an earlier age. In addition, individuals with disabilities have a higher risk of osteoporosis. They are more likely to use medications that contribute to the loss of bone mass. Challenges with mobility, weight bearing, physical activities, and muscle strength can all impact on the ability to build and maintain bone mass. OMRDD plans to enhance the early identification, prevention, and treatment of osteoporosis for individuals with developmental disabilities through the development and distribution of educational materials consistent with best practices.

Medication Management

OMRDD intends to foster autonomy and skill development in individuals we serve. The ability to self-administer medication often is a determining factor in decisions regarding residential alternatives, vocational choices, and leisure time/vacation opportunities.



OMRDD regulations define a person as self-medicating if they can recognize the time a medication is to be taken, identify the container the medication is in, open the correct container, remove the correct dosage and close the container, obtain appropriate fluids or materials needed to ingest, apply, inject or use as ordered, and return medication to the appropriate storage area.

Traditionally, self-administration has been narrowly defined. However, with the advent of new technology, OMRDD is broadening its interpretation to include different kinds of technologies that can assist individuals to correctly self-administer their own medications. One technology that shows particular promise is the array of “pill boxes,” otherwise known as pill or medication organizers that can accommodate different individual’s ability levels. Sometimes called assistive devices or independent living aids, pill organizers can assist an individual to live and function more independently. Pill organizers range in size and complexity from large items that organize all of the medications that a person must take for an entire month, to small containers that fit into a pocket, perfect for remembering medications that must be taken when the person is not at home.

The newer generation of pill organizers has built in clocks and alarms to assist the person in recognizing the time medication is to be taken. The clocks have large digital displays that are easy to read. Many of the clocks include an alarm to remind a person when it is time to take medications. Some of the alarms are not just noises, but an actual voice that calls the person (e.g.: “it is time to take your pills”). This type of system aids individuals in knowing what the alarm is for and what they need to do when it sounds. Others, particularly on the smaller models, can be set to vibrate as well as alarm, or to just vibrate so that they are more discreet while the person is out in the community. Virtually all of the alarms repeat at a preset interval until the individual opens the correct compartment to take their medications. The alarms on many of the pill organizers only need to be set once and then will automatically repeat everyday, eliminating the need for the individual to remember to reset the alarm.

During the period of this Plan, OMRDD will expand its efforts in the use of technology to enhance the ability of individuals to self-administer medication.

Nutrition

Community living is an integral part of people’s lives. Supporting individuals’ nutrition needs through additional services will improve their success and promote integration into the community.

Since some people have individualized nutritional needs specific to their disabilities and health status, programs designed for the general population are often minimally effective with the people OMRDD serves. Therefore, Developmental Disabilities Services Office (DDSO) dietitians must often design their own programs and materials to meet the developmental level of specific individuals.

The Nutrition Care Process is a dynamic systemic approach to providing high quality nutrition care that was just developed by the American Dietetic Association for use by dietitians nationwide. The four components of the process are Nutrition Assessment, Nutrition Diagnosis, Nutrition Intervention, and Nutrition Monitoring and Evaluation.

The process defines a common language and terminology that allows clinical nutrition practice to be more measurable and consistent. This innovative approach is designed to improve consistency and quality of individualized nutrition care.

This process establishes an enhanced system for tracking and improving predictability of individual outcomes of nutrition care allowing OMRDD to better measure the success of nutrition care and evaluate where improvements can be made to provide an optimal quality of care for the people that are served. Since good nutrition care has been shown in the past, and especially through recent scientific studies, to greatly improve an individual’s health status and quality of life, the individuals OMRDD supports will reap this enhanced benefit in their own health and daily lives.

With the collaboration of dietitians on a statewide basis, the nutritional needs of individuals with developmental disabilities for community living will be further defined. Also the identification and dissemination of best nutrition practices across the state will provide a resource for fellow dietitians to use to supplement nutrition care. Pinpointing areas of need will result in the development of future programs, materials, and supports to meet specific nutritional needs of individuals, and support their lives in the community. Additionally, Chapter 324 of the Laws of 2008 requires meals served at OMRDD operated or certified residential programs be served at

appropriate times and in as normal a manner as possible, and prohibits altering the composition or timing of meals for punishment or disciplinary reasons, behavior modification or convenience of staff.

Article 16 Clinic Services

Article 16 clinics are one of the main vehicles by which OMRDD provides necessary long-term therapies to persons with developmental disabilities. Activities related to the administration of Article 16 clinics include management and oversight of the detailed review and approval process for new Article 16 clinic programs. Activities also include: responsibility for implementation of special initiatives, such as the conversion of Article 16 clinics to rate-based HCBS waiver programs, and the collaborative development of a joint Department of Health (DOH)/OMRDD certification process for clinics; assistance to provider agency staff with issues related to Medicaid billing for Article 16 clinic services; and the provision of program and policy technical assistance to DDSOs dealing with clinic issues.

In 2005 a major clinic restructuring initiative began. Its goal was to convert 26 joint partner Article 16 clinics (in which OMRDD holds the operating certificate but a voluntary non-profit agency provides the clinic services) into either independent “free-standing” Article 16 clinics, or to incorporate clinical services into day or residential program rates. This was completed in 2007. Effective coordination and consistent communication with the DDSO district offices and the voluntary agency joint partner clinics ensured that all individuals affected by the conversion continued to receive necessary and appropriate clinical services.

OMRDD accomplishments also include working with both DOH officials who regulate and set policy for Public Health Law Article 28 clinics, and with OMRDD providers who are licensed to operate Article 28 clinics that provide medical and long-term clinical therapeutic services to persons with developmental disabilities. OMRDD provided technical assistance to nine upstate provider agencies impacted by the policy and program decisions of DOH and other State agencies regarding the 2005 New Dimensions in Health Care settlement agreement. By incorporating clinical services into rate-based HCBS waiver programs, all appropriate services previously provided to persons with developmental disabilities by the New Dimensions Article 28 part-time or extension clinics have been maintained.

Certificate of Need (CON) reform is part of the restructuring of NYS’s health care system to strengthen primary and preventive care, and is necessary for the success of the State’s multi-year initiative to reform Medicaid reimbursement. The intent of the CON reform is to ensure that the appropriate agency has lead oversight for clinic services provided; that the certification rules are clear to providers; and that the application of threshold guidelines (i.e., maximum number of visits or services in a given timeframe) does not result in a lack of coordinated care for persons with multiple disabilities or conditions. The Certificate of Need reform was finalized as a result of the interagency collaborative endeavor among DOH, the Office of Mental Health (OMH), the Office of Alcohol and Substance Abuse Services (OASAS), and OMRDD.

OMRDD will implement the CON reform strategies across all relevant settings over the next year. OMRDD and DOH have identified more than 40 OMRDD providers currently licensed to operate Article 28 clinics that focus on the provision of medical and long-term habilitative therapy services to persons with developmental disabilities. Of the 40, approximately 27 DOH Article 28 clinics provide a substantial amount of long-term habilitative therapies to persons with developmental disabilities that fall within the service delivery thresholds for OMRDD/DOH joint clinic certification. OMRDD is working to streamline the OMRDD CON process in recognition that the required certification adjustments are consistent with existing clinic service provision.

Behavioral Health

The quality of every person’s life is affected by his or her behavioral health. The principles of individualized services and person centered outcomes must inform and shape every intervention designed to assist the individuals OMRDD and its providers serve. This includes making behavioral changes that lead to personal growth and a better quality of life. Therefore intervention plans must be rooted in a clear understanding of the desires and needs that motivate each person’s behavior, based on observation and analysis. Staff need to recognize behavior as a means of communication and support individuals with developmental disabilities in positive, nurturing environments that ensure respect for basic rights and safety.

In the context of a changing workforce, providers of care must be able to integrate new clinical and direct care staff

into a healthcare community whose core values are consistently reflected in the approach to behavioral assessment and intervention. OMRDD has for many years provided workforce training in positive behavioral supports, and crisis management and intervention. In the future, as interagency collaborative efforts evolve and our workforce continues to change and include new members from varied backgrounds, OMRDD and other providers will have to deliver a clear and consistent system of education and training in basic principles of behavioral change, functional behavior assessment, and individualized intervention planning. In this context, the current curriculum called Strategies for Crisis Intervention and Prevention-Revised (SCIP-R) is being revised.

The present Strategies for Crisis Intervention and Prevention-Revised (SCIP-R) curriculum was issued for use across the state in February of 1998. At that time, it had been expanded from the previous edition to include greater emphasis on using positive strategies when addressing challenging behaviors, and additional material was included regarding crisis prevention. The focus of the new curriculum is intended to shift the philosophy of staff from behavior control and crisis intervention to that of fostering positive and functional relationships, environments, communication, and respect. These strategies have been shown to reduce the likelihood of challenging behaviors on the part of individuals being served. The revised curriculum will also continue to teach staff the necessary skills to assure health and safety of individuals and staff alike, but will clearly emphasize that “hands-on” or physical interventions are only to be used as a last resort when the individual is representing an immediate health and safety risk to self or others.

Changes are also being made to several of the personal (physical) intervention techniques with a focus on ensuring, should a behavioral crisis occur, the health and safety of all persons involved.

Training in SCIP-R was intended to provide only one component of the extensive training staff receives. In the Guidelines for SCIP-R Training and Implementation, OMRDD recommends that staff should also receive training in Positive Approaches to Behavior Change or a similar training program that emphasizes positive behavior support strategies. The SCIP-R curriculum has been implemented by state and voluntary agencies serving the OMRDD population with no changes or amendments from the time it was issued. While the curriculum has been successful in providing staff with necessary resources to address crisis intervention and prevention over the past ten years, revisions were needed. The decision to revise SCIP-R was based on material becoming dated and on the agency’s renewed emphasis on positive and proactive approaches to behavior management. There is also the imperative to rely less on the use of physical interventions across all state agencies in response to participation on the Interagency Restraint and Crisis Intervention Techniques Committee, which was recently extended by Chapter 470 of the laws of 2008.

Electronic Records

Moving people’s medical records from paper and physical filing systems to computers and their super storage capacities supports better quality of care, and creates other efficiencies for individuals, providers, and health payment systems.

For individuals, access to good care becomes easier and safer when records can easily be shared. Important information -- such as blood type, prescribed drugs, medical conditions, and other aspects of their medical history -- can be quickly retrieved. Electronic Medical Records (EMR) allows access to clinical information that makes clinical decision-making easier and more accurate. Quick access to medical records can be lifesaving if an emergency occurs and answers to those questions are needed during the emergency decision-making process. EMRs improve individuals’ care. They are equipped with automated reminders, protocols, and alerts for primary and preventative care. This type of medical care tracking helps to reduce the incidence of secondary disabilities and promotes overall improvement in health status. Protocols and clinical decision pathways assist physicians and other health care providers to ensure that care is provided efficiently and comprehensively.

Money is saved by using electronic medical records; not just the cost of paper and file folders, but also the cost of labor and space. Using EMRs frees up office space that would normally be dedicated to storing paper records. Data are quickly and easily retrieved by typing a few identifying keystrokes, as opposed to searching through thousands of pages of information. The efficiencies created by an EMR system save the system many thousands of dollars, providing a quick return on investment.

OMRDD has taken its first steps into the electronic record era with the development of the Medical Appointment Tracking System (MATS). MATS was designed by a group of information management solutions staff and end

users. It has been piloted in several DDSOs and has undergone several enhancements as a result of the pilot. The lessons learned from the MATS project will assist OMRDD in moving forward with electronic records.

Medicaid Managed Care

Health care services under Medicaid coverage are provided through both fee-for-service providers and managed care organizations. In NYS, most Medicaid recipients are required to join a managed care plan to receive their Medicaid covered health care services. Individuals with developmental disabilities being served by OMRDD are, for the most part, exempt from mandatory enrollment in a managed care plan and can choose to receive their health care through fee-for-service providers. Individuals who reside in ICFs/DD, who are participants in OMRDD's Home and Community Based Services (HCBS) waiver, or who have needs and characteristics similar to those receiving these services may enroll voluntarily in a Medicaid managed care plan but are not required to do so. These exemptions from mandatory enrollment were enacted into law at the inception of the Medicaid managed care program. OMRDD is committed to maintaining choice for the individuals it serves in order to ensure their ongoing access to the most appropriate health care providers and services.

Medicare

Medicare is the federal government program that provides health insurance coverage for individuals who are 65 or older, or under 65 and receiving Social Security Disability benefits. The Center for Medicare and Medicaid Services oversees Medicare. Medicare provides coverage for both hospital (Part A) and medical (Part B) services for eligible individuals.

Medicare's drug benefit (Part D), which began on January 1, 2006, is outpatient prescription drug coverage available only through private companies who contract with Medicare. Individuals with both Medicaid and Medicare (dually eligible) qualify for a Low Income Subsidy (LIS), are automatically and randomly assigned to subsidized plans, and can change plans monthly to meet their needs. There are approximately 43,000 people served in the OMRDD system who are enrolled in Part D plans. The coverage for these individuals must be reviewed annually to ensure the drug plan will continue to meet his or her medication needs.

The array of plans and drugs covered by each plan that qualify for subsidized status changes every year. Individuals who remained in their auto-assigned plans are reassigned by CMS; individuals who choose new plans must determine if their plan will continue to be fully subsidized and if not, act to enroll in a new plan or pay a monthly premium within a short enrollment timeframe. This often places great demands on the agency workforce to research each available plan to match the particular medication needs of each individual.

CMS has indicated that for individuals who do not have the ability to choose and act on a plan, a personal representative must be authorized under state law. OMRDD developed regulation 14 NYCRR Subpart 635-11 that allows authorized individuals to enroll persons in a Medicare Part D plan and deal with any part of the appeals process.

OMRDD will continue to look for approaches to minimize annual reassignment demands, and will monitor the development and suitability of managed care Medicare Advantage Special Needs Plans (SNP) for the individuals the agency supports.

Advance Health Care Directives and Surrogate Decision-Making

The authority of Surrogate Decision Making Committees (SDMCs) to make major health care decisions for individuals with no legal guardian or qualified family member has been steadily expanded over the years. Use of the SDMC process enables such people to receive informed and timely health care treatment decisions based on the advice of trained volunteers and health care professionals.

Recent legislation expands SDMC authority to act on behalf of a person who has been discharged from OMRDD programs and had not used SDMC in the past, and to make decisions to withhold or withdraw life sustaining treatment from a person with developmental disabilities who lacks capacity and who does not have a legal guardian or qualified family member available to make such decisions on their behalf. The newly enacted laws would also permit the Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD) to contract with community dispute resolution centers for local administration of SDMC proceedings.

Other recent legislation provides for a simplified advance health care directive process for persons with developmental disabilities. The legislation authorized a two-year demonstration program for the use of a new advance health care directive (i.e., proxy). The new health care proxy would, at the person's option, authorize the health care agent to make health care decisions immediately prior to such person becoming incapacitated. Such health care decisions would be made by the agent in consultation with the individual and the treating physician. Implementation requires OMRDD and DOH to approve the new form and also requires both agencies, in conjunction with parents, advocates, health care providers, and other interested stakeholders to study and report on the form's use to the Governor and Legislature.

Outcomes and Performance Measures

The following outcomes and performance measures have been developed to define the key focus areas for work activities related to maximizing personal health and growth.

Outcome:

OMRDD will enhance the early identification, prevention, and treatment of health related conditions for individuals with developmental disabilities

Performance Measure:

- Increase in the number of individuals reporting satisfactory health status.
- Increase in the number of favorable responses to National Core Indicators (NCI) Consumer Survey health related indicators.

Outcome:

OMRDD will implement state of the art practices to improve the behavioral health of people served.

Performance Measure:

- Development of training materials that outline the principles and practice of functional behavioral assessment.

Outcome:

OMRDD will increase the use of electronic recordkeeping to enhance the clinical decision-making of clinical staff providing health care to persons with developmental disabilities.

Performance Measures:

- Expansion of the use of Medical Appointment Tracking System (MATS) beyond the pilot districts.
- Development of electronic record-keeping protocols to enhance efficiencies and communications.

Outcome:

OMRDD will support individuals with developmental disabilities to receive needed medical and dental care by implementing standardized practices which facilitate needed medical and dental procedures through the development and dissemination of policy and staff training curriculum in Medical Immobilization and Protective Stabilization (MIPS).

Performance Measure:

- Development of a training curriculum on MIPS policy and standardized practices.



Outcome:

OMRDD will enhance the consistency and quality of individualized nutrition care through the training and implementation of the “Nutrition Care Process” statewide.

Performance Measure:

- Increase in the number of individuals with developmental disabilities reporting they eat healthy foods on a regular basis.

Chapter 9: Themes Affecting All Services

Quality Management

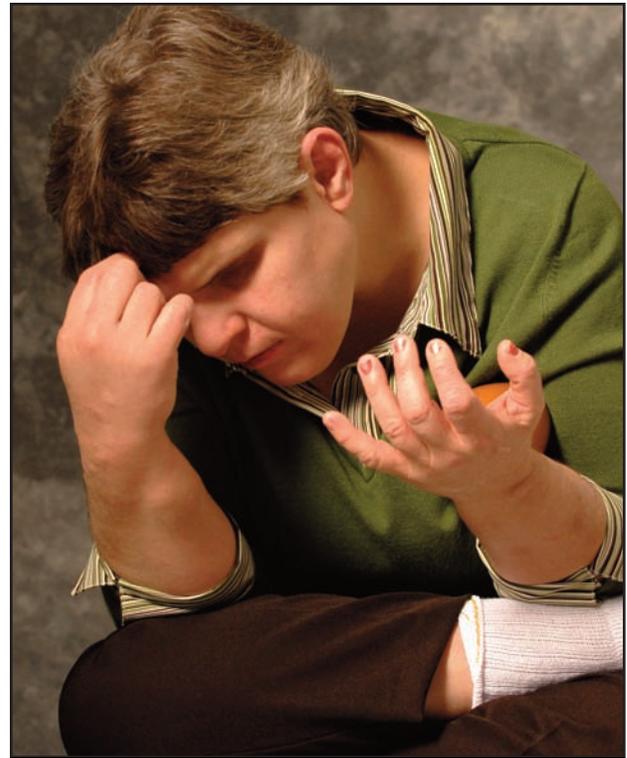
As a central component of OMRDD's transformation agenda, the Division of Quality Assurance has been renamed the Division of Quality Management (DQM). As such, DQM will coordinate OMRDD's continuous efforts to develop a comprehensive statewide quality management strategy that stems from OMRDD's mission, vision, values and guiding principles. OMRDD's quality management strategy will be based upon a commitment to shared leadership, learning, and organizational development that will build capacity throughout the service system to achieve the fundamental goal of enhancing the quality of services and outcomes for individuals with developmental disabilities so that they can live richer lives.

In order for these positive changes to succeed, quality management and continuous quality improvement processes must be integrated into ongoing and daily operations at all levels of the organization and these principles should ultimately become assimilated into everyday thinking. DQM actively promotes and coordinates OMRDD's statewide comprehensive quality management strategy. DQM also will be incorporating quality management and continuous quality management principles in the division's traditional regulatory and enforcement responsibilities. Over the long-term, these activities will lead to a comprehensive, interactive, and collaborative "People First" approach to assuring and improving quality services and individualized outcomes. The following illuminate improvement principles in quality assurance operations.

Consumerism Outcome Management Plan Agency Self Survey. DQM will continue to promote excellence in the service delivery system by using the Consumerism Outcome Management Plan Agency Self Survey (COMPASS) program to promote high-quality, person centered supports and services. COMPASS agencies will serve as role models to other agencies by demonstrating innovative service delivery approaches which exemplify person centered values. COMPASS agencies will continue to provide training to the provider community at DQM provider forums and to Boards of Directors of both newly established agencies and agencies beginning to provide new services. Consistent with quality management principles, the COMPASS program will be enhanced over the next five years by:

- Reviewing and revising the COMPASS criteria to ensure consistency with OMRDD's vision and mission statements; and
- Increasing the number of COMPASS agencies, improving recognition of COMPASS agencies, and enhancing incentives for agency participation.

DQM also intends to promote system-wide continuous quality improvement initiatives by gathering and using information obtained from individuals with developmental disabilities, their families, and provider agencies to revise survey protocols to better measure person centered values and focus on the four priority outcomes of home, health, productive activities, and relationships. A self-advocate is currently assigned to DQM to meet with self-advocacy groups and attend self-



advocacy forums, as well as distribute the “Know Your Rights” manual to developmental disability and advocate groups. DQM staff also routinely hold participant forums to obtain input. Efforts to strengthen information gathering and sharing will include establishment of a Consumer/Family Advisory Council, the reinstatement of a quarterly newsletter to advise the provider community of current issues and best practices, and regional meetings to obtain input from individuals and families.

Incident Reporting Management Application. OMRDD continues to implement the web-based application for incident reporting called the Incident Reporting Management Application (IRMA). IRMA has been implemented within state operated programs in all districts across the state; implementation of IRMA among voluntary operated agencies is just beginning. IRMA provides the ability to capture data from the OMRDD incident reporting forms as well as follow-up information related to incident investigations. The implementation of IRMA will result in report-generating capacity to enable identification of trends, thus, aiding in the statewide quality management of incidents. One new area of interest is related to safety awareness and accident prevention for people with developmental disabilities. Analysis of incident data will be used to guide development of targeted safety awareness campaigns for people with developmental disabilities.

Surveys and certification. To ensure the provision of services in compliance with established laws, regulations and policies DQM will:

- Continue to conduct routine reviews of all programs and services. DQM has initiated a team project to enhance the efficiency of the survey process used for program recertifications. While the current process used is largely outcome based, it is anticipated the revised process will better promote the core values expressed in OMRDD’s vision and mission statements by increasing focus on individual satisfaction and agencies’ effectiveness.
- Continue to identify providers whose inability to protect and ensure the health, welfare, or safety of the citizens of NYS who have a developmental disability and implement appropriate administrative remedial actions. This will ensure that the Center for Medicare and Medicaid Services (CMS) survey and certification requirements are met, and the Office of the Medicaid Inspector General (OMIG) protocols for program integrity are satisfied.
- Make comparable data sets regarding the quality of services provided by agencies available to assist individuals and families who are seeking services make better informed choices.

National Core Indicators. To promote excellence in services which reflect person centered values and which can be measured against the services offered in other parts of the country, OMRDD is now a participating member of the National Core Indicators (NCI) project sponsored by the National Association of State Directors of Developmental Disabilities Services and coordinated through the Human Service Research Institute (HSRI). The NCI project uses several tools to assess overall systems performance on quality of life indicators, with the Consumer Survey as the key tool. Additional assessments of service quality indicators and systems data are conducted through family surveys, provider surveys, and reviews of existing data sources. These additional assessments target staff recruitment and retention, employment statistics, mortality and board compositions, in addition to satisfaction with services. DQM provides guidance to this project by chairing the NCI Advisory Committee. HSRI provides training and support to the participating states, and helps analyze the data to enable performance comparisons across states. OMRDD will utilize NCI results in various quality management efforts, including evaluation of the quality of provider services, evaluation of the effectiveness of services, and evaluation of the Systems Transformation, Systems Change grant activities. The sample size of those surveyed as part of the NCI project is anticipated to increase significantly the next five years.

Systems and performance accountability. There is a need for a strong focus on fiscal, systems, and performance accountability, given the significant level of resources under OMRDD’s stewardship – funding supports and services to nearly 125,000 individuals with developmental disabilities delivered by OMRDD and over 700 non-profit providers.

OMRDD has a strong commitment to enhance program integrity and transparency, accountability, and quality management. To this end, OMRDD has invested in a comprehensive and effective monitoring structure to oversee the fiscal integrity and corporate accountability of the non-profit voluntary agencies that provide services to the individuals with developmental disabilities.



In February 2008, the Bureau of Compliance Management was transferred to DQM from the Division of Fiscal and Administrative Solutions (DFAS). The Bureau continues to coordinate with DFAS, and is responsible for the oversight of the fiscal and corporate accountability of provider agencies.

OMRDD's multi-faceted oversight structure is comprised of systems that review the most critical aspects of agency financial management and accountability through our Limited Fiscal Review; desk reviews (annual calendar of 70 desk reviews ensures appropriate billing) and field audits; targeted reviews that assess the validity of allegations and complaints; and targeted reviews based on data analysis and fiscal risk assessment.

OMRDD has worked with the provider community to ensure that our systems are based on clear billing and documentation standards and that appropriate training is provided on those standards.

Over the next five years, OMRDD will seek to assess the degree to which provider agencies have developed and implemented quality management self-assessment systems that provide mechanisms to strengthen program integrity and fiscal accountability, and to prevent waste, fraud, abuse, and the imprudent use of government resources.

OMRDD will continue to conduct Limited Fiscal Reviews (that focus on board governance, oversight of the executive director, internal controls, use of agency resources, and fiscal viability), Medicaid Billing and Claiming Reviews, and targeted reviews of provider agencies based on risk assessment related data analyses. OMRDD expects to conduct over 500 field audits during the next five year period. OMRDD fiscal audit activity is designed to assess the extent to which agencies are using public resources appropriately for the benefit of persons served which enables persons with developmental disabilities to enjoy meaningful relationships with friends, family and others in their lives, experience personal health and growth, live in the home of their choice, and fully participate in their communities.

Nurturing partnerships and collaborations is a key OMRDD guiding principle. OMRDD strives to strengthen corporate governance and accountability and protect public resources through interagency collaborations. The continuation of our collaborative efforts with the Office of the Medicaid Inspector General (OMIG) and other agencies that oversee programs and resources for people with developmental disabilities will be a key focus area in the coming years.

OMRDD will collaborate with the OMIG on expanded reviews of provider Medicaid billings and other Medicaid related reviews. Referrals will also continue to be made to the OMIG when there is suspected Medicaid waste, fraud, or other abuse involving Medicaid, or there is a lack of documentation to support Medicaid claims.

Additionally, OMRDD has been partnering with the Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD), the Office of Mental Health (OMH), and the Office of Alcohol and Substance Abuse Services (OASAS) to formulate a series of recommendations to improve corporate governance of providers. These recommendations are designed to create greater corporate accountability, improve program integrity, and reduce the likelihood of fraud, overpayments and imprudent use of public funds. It is anticipated that these recommendations will result in the promulgation of regulations that contain board oversight enhancements as well as mechanisms that will enhance internal controls, ethics, financial reporting and certifications, and cost control policies.

These interagency collaborations strengthen the mechanisms available to OMRDD to ensure that agencies use public resources appropriately for the benefit of the individuals served.

Board governance. OMRDD requires all board members of new agencies to attend OMRDD specific board training. This training provides an overview of OMRDD and makes the trainees aware of issues agencies may face in providing OMRDD services. OMRDD also provides board training to agencies experiencing fiscal and/or program quality difficulties. In addition, OMRDD will provide board training to all agencies that request it and has developed trainings to address specific board concerns. Training has been developed to address board members' roles and to help boards do their own self-assessments.

OMRDD will be rejoining the State Board Training Consortium, which will provide additional board training opportunities for non-profit providers. OMRDD, in conjunction with DOH, OMH, OCFS, and OASAS will enter into a contract with the Council of Community Services of NYS, and the Council of Community Services will, in turn, offer free board training to all board members of non-profit agencies funded by the participating agencies. Training topics include duties and responsibilities, ethics, fund development, human resources, accounting basics,

board development, strategic planning, audits, and understanding legal obligations. The Council will also provide some targeted one-on-one agency board training. As OMRDD believes that an effective board is integral to a successful agency, this training should be particularly helpful to emerging agencies.

Personal Responsibility

OMRDD recognizes that providing high quality supports and services to individuals with developmental disabilities demands an appropriate level of personal responsibility and fiscal accountability, especially given the number of people receiving or in need of OMRDD services. Further, OMRDD recognizes the need to insure that non-profit providers, parents, families, advocates, and the individual with developmental disabilities receiving or seeking supports and services funded by Medicaid or Medicare, fully understand that individual responsibility cannot be lost or dismissed in the process. All who participate in the process, not just State government and the non-profit providers are responsible for the outcomes. OMRDD and its partnering non-profit provider associations and their members, have set in motion plans that will not only require families and individuals with developmental disabilities to apply for benefits (Medicaid, Medicare, etc.), but will educate and assist them to do so when seeking supports and services funded by Medicaid and/or Medicare. This action assures that federal financial participation is achieved for every eligible individual, and, in turn, generates savings in the NYS budget.

Home and Community Based Services Renewal

As required by federal regulation, OMRDD will submit the fourth renewal of the Home and Community Based Services (HCBS) waiver in 2009. The waiver currently has more than 62,000 enrollees. Due to the large number of enrollees, many bureaus within OMRDD contribute to the management of the program. The renewal process will begin in late 2008 to ensure that all affected parties have an opportunity to comment. As part of the renewal process, OMRDD will seek opportunities to further advance the transformational agenda around individualized services. The Department of Health (DOH), as the single State Medicaid Agency, will be working collaboratively with OMRDD in preparing this renewal application for submission to federal CMS. The new waiver agreement must be in place by October 1, 2009.

Workforce Development

Campaign to reduce abuse and neglect. As reported in Chapter 7, OMRDD announced in June 2008, a multifaceted approach to reducing serious incidents, abuse, and neglect in its service system. Foremost in this new effort is the creation of the Division of Workforce and Talent Development, which is designed to bring leadership, heightened investment and oversight to the agency efforts toward workforce enhancement. Central to this effort is the desire to improve the system's capacity to develop and sustain relationships between service recipients and staff, which are critical to achieving service systems outcomes on many levels. To achieve these goals, OMRDD is expanding and refocusing training and supervision.

The quality of care for people with developmental disabilities is tied to the positive relationships in people's lives – especially those with staff who are deeply involved in their day to day activities. It is with this in mind that OMRDD is accelerating the development and implementation of the following tactical plan:

- Intensify oversight of stress-intensive living or program environments;
- Expand and refocus training for staff of voluntary provider agencies; and
- Engage in discussions with OMRDD workforce and labor/management groups on ways to reduce stress in the work environment, and methods to better manage the impact on all staff when a particular staff person has acted in an unacceptable manner.

Commissioner Ritter has also created a new Office of Investigations and Internal Affairs to improve OMRDD's capacity to investigate reports of abuse and neglect, among other incidents. OMRDD is partnering with external groups who have expertise in workforce issues, abuse and neglect, and organizational cultures. The State of New York University at Albany School of Social Welfare has pledged such a partnership. Eventually, these partnerships will grow beyond the initial arrangement with the University at Albany, to help establish a corporate culture within the OMRDD-funded system in which there will be zero tolerance for abuse and neglect. This abuse prevention focus will be embedded in the agency's overall quality management strategy, directed at staff and their interactions with people with disabilities.



This new campaign to reduce abuse and neglect will involve a three-part approach:

1. **A Risk Appraisal** portion will use well-established national research on institutional abuse to create a Risk Appraisal Profile for residential units.
2. **A Prescriptive Prevention Strategy** will be developed for each unit within designated facilities that directly reflects that unit's risk profile. The intent in the Prescriptive Package is not to focus on any individual, staff or system-related problem, but rather to approach the problems jointly in an effort to reduce or eliminate, to the greatest extent possible, the factors which make it more likely that abuse will occur.
3. **An Abuse Awareness Campaign** will target system-wide public education and marketing. Aimed at staff of all levels, the theme of this portion of the project will be the preservation and enhancement of dignity and respect for the individuals OMRDD supports. To the extent that OMRDD is able to positively impact upon the nature of the relationship between individuals and staff, and promote a heightened awareness on the part of staff to the importance of maintaining people's dignity and respect, OMRDD will decrease the likelihood that staff will abuse individuals or tolerate abusive behavior from their peers.

Technical Assistance Grant. In 2006, the CMS awarded OMRDD a one-year grant of technical assistance through the newly created National Direct Service Workforce Resource Center.

Beginning in 2006, OMRDD used this grant for assistance as it worked with a multi-stakeholder Advisory Committee to examine a wide range of direct support workforce issues centered on three areas: 1) training; 2) career paths and improving recruitment and retention of workers; and 3) developing the workforce that serves self-directing individuals. The Resource Center provided technical assistance in the form of responses to specific research questions developed by the Committee and OMRDD staff. The final report on the activities of this year-long grant, entitled "Ensuring Stability and Quality in New York State's Direct Support Workforce," (available at http://www.omr.state.ny.us/images/hp_finalgrant.pdf) contains a summary of the findings, including what the Advisory Committee learned through OMRDD staff research and the input from the Resource Center, an annotated bibliography of the best resources on direct support workforce information and a set of policy recommendations aimed at strengthening OMRDD's direct support workforce.

At the conclusion of the grant in August 2007, OMRDD was awarded an additional year of technical assistance from the Resource Center to continue the activities of the grant. In this capacity, the Advisory Committee has overseen the implementation and evaluation of \$2.5 million in demonstration grants to 17 non-profit agencies and provider associations aimed at improving the quality of care for individuals with developmental disabilities through the enhancement of direct support education and training.

Real Choice Systems Change, Systems Transformation Grant: Direct Support Workforce and Clinical Workforce Groups. The Real Choice Systems Change, Systems Transformation Grant has become a major vehicle for strategic change in how OMRDD conducts business. This grant was previously described in Chapter 4 called Person First – Person Centered and Self-Directed Supports. Among the strategies contained in the work plan developed by the Choice Subcommittee was one devoted to the recruitment and retention of a high quality workforce – from both a frontline and clinical perspective. Because the workforce-related activities identified in the Strategic Plan were so closely aligned with the ongoing work of the Technical Assistance grant, the work of the two grants has been carried out by combining the membership of each grant's stakeholder group into a single "Direct Support Workforce (DSW) Advisory Committee."

A separate work group to guide future developments within OMRDD to enhance the clinical workforce was established in November 2007. This workgroup intends to study current and future workforce needs and shortages in clinical staffing, along with a plan to implement recommendations generated by the activities of the workgroup. The workgroup has created two surveys to more fully assess workforce capacity needs, regional differences and cost impacts of clinical services, particularly for high-need individuals and geographic areas where recruitment of clinicians is more difficult. One survey is designed to be completed by directors of human resources, while the other is designed for clinicians from a variety of disciplines to complete. The workgroup will analyze the data collected, develop and implement interventions, and measure the effectiveness of these interventions. Through these changes OMRDD envisions systemic improvement in the retention and recruitment of qualified clinical staff.



State Employees Training Issues Committee. In the fall of 2007, a State Employees Training Issues Committee (SETI), comprised of Central Office and DDSO staff involved in the administration of the Developmental Aide and Developmental Assistant Traineeships, was charged with a critical review of the following four training elements. A status update on each of the four charges appears below:

- **Establish mandated core topics and outlines for each topic.** The group has devoted much of its initial energy to the issue of Developmental Assistant supervisory training as a factor which plays a critical role in Developmental Aide staff retention. To that end, a grid summarizing supervisory training topics for Developmental Assistant trainees was developed. Each Developmental Disability Services Office (DDSO) was given an opportunity to update its respective status. Based on this information, DDSOs have begun to modify their training curricula based on the experiences and success of their DDSO counterparts. A preliminary recommendation of SETI is to develop standardized basic outlines for a core group of supervisory topics that will ensure consistent, sound principles across the State.
- **Identify methods for improving mentoring and supervisory skills and ways to implement these improvements.** In addition to the above-mentioned Developmental Assistant supervisory training inventory, the SETI group has shared best practices regarding Supervisory Mentoring Programs and is reviewing mentoring material for possible use in the DDSOs. The group is also exploring the creation of a DVD, with Commissioner Ritter welcoming new supervisors and other employees.
- **Evaluate College of Direct Support as a supplementary training tool.** The SETI has undertaken a thorough review of the College of Direct Support (CDS) as a supplement to OMRDD's current DDSO-based direct care training programs. A group of forward-thinking Central Office and DDSO staff have been granted access to the online curriculum and have shared their comments on course content. Specifically, their review has been focused on the suitability of the material for the OMRDD frontline workforce as well as possible differences between the information provided in the courses and the information OMRDD provides in its current training curriculum. Following a compilation of the comments received from reviewers, staff will be comparing the CDS to other available online training programs geared toward direct support professionals.
- **Reexamine the role of the Direct Care Competencies in Developmental Aide training.** The SETI is reviewing direct care competencies in Developmental Aide training with an eye toward incorporating OMRDD's revised Vision, Mission, Values and Principles so that "helping people with developmental disabilities live richer lives" resonates loud and clear throughout the competencies.

The DSW Advisory Committee received updates from the SETI Workgroup on OMRDD's internal review of its state direct support workforce core competencies and training curriculum for developmental aides and frontline supervisors. Additionally, the Resource Center worked directly with the SETI group in this area. While OMRDD staff has kept the DSW updated on the progress of the SETI within the overall context of the agency's workforce initiatives, the DSW has played no formal advisory role in the SETI's activities.

Traineeship Re-engineering Workgroup. In June 2008, Commissioner Ritter directed Central Office and DDSO talent development, affirmative action, and human resources management to explore possible ways to re-engineer the agency's current Developmental Aide Traineeship to reduce the level of attrition, reported to be in excess of 40% in some DDSOs. The group will examine the current processes for recruiting, hiring and welcoming staff; the conduct of the Developmental Aide Traineeship; and the reasons why trainees leave the program. The group's charge included the following outcomes: 1) suggest changes for process improvement and cost savings that can be implemented by OMRDD; and 2) record broader suggested changes not implemented by OMRDD for discussion with other stakeholders and partners. The group will present a preliminary report to the Commissioner by late 2008.

Distance Education and Learning System online courses. Through its Distance Education and Learning (DEAL) project, OMRDD has established an accessible and cost efficient online training institute. The DEAL project has enabled OMRDD to become a pioneer among its state agency counterparts in offering educational programs in a distance learning format. This is an excellent training opportunity for anyone concerned or involved with the developmental disabilities community. During the DEAL start-up phase, the "Home and Community Based Services (HSBS) Waiver" course was offered on a pilot basis. The pilot was successful and the Waiver course is now offered online on a regular basis. In 2005, "Incident Reporting" became the second DEAL course to be offered online. "Introduction to Personal Allowance" has joined its predecessors to become the third DEAL course now offered online. At the moment, Incident Reporting and Personal Allowance are temporarily unavailable while

they are being updated to reflect the enactment of Jonathan's Law and changes in benefit levels for individuals with developmental disabilities, respectively.

Clinical staffing. Provision of a quality, stable workforce that supports the OMRDD Mission of helping people with developmental disabilities lead richer lives is pivotal to providing people opportunities to access the supports and services they need and to enjoy meaningful relationships with others. The role of the Psychologist in providing clinical and behavioral support is central to this mission. At present, OMRDD faces a critical shortage of clinical staff, and anticipated workforce attrition (through retirement and staff turnover) is likely to exacerbate the problem. Psychologists' exposure to the needs and issues of the intellectual and developmental disabilities population is limited in many graduate programs; few are aware of the opportunities that exist. OMRDD is currently in the process of developing internship and externship opportunities for graduate students, with the intention of extending employment possibilities to these students upon graduation. Additionally, OMRDD is actively working to increase opportunities for clinical staff's professional growth and development, with an eye toward improving services for our individuals. Multiple videoconferences focusing on cutting-edge therapies and innovative practitioners have been held in the past year. OMRDD is presently involved in an inter-agency collaboration with OMH to provide training for psychologists from both agencies on a state-of-the-art, soon to be released intellectual assessment instrument. Interagency training between OMH and OMRDD, focusing on treatment and placement issues for individuals who are dually diagnosed and forensically-involved, is being discussed and planned.

Overtime management. Newly enacted legislation, Chapter 493 of the Laws of 2008, amends both NYS labor and education law, and prohibits the assignment of mandatory overtime to nurses, except in limited circumstances, effective June 2009. The law applies only to OMRDD state-operated programs; voluntary agencies are excluded. The law applies to both Registered Nurses and Licensed Practical Nurses. Specifically, no provider covered under the law shall require a nurse to work more than the nurse's regularly scheduled hours, except in an emergency. The bill does not limit voluntary overtime. OMRDD will be working over the next year to assess implications and develop implementation standards for state-operated programs.

Additionally, Chapter 327 of the Laws of 2008 requires OMRDD to conduct an evaluation and study of direct care staffing policies, including overtime. OMRDD will convene a workgroup to examine work schedules for direct support employees, and the numbers of consecutive hours that a direct support employee may work within a specific period. The workgroup is chaired by Commissioner Ritter, composed of several state agencies, and receiving input from various stakeholders including family members, community-based organizations, and labor unions that represent direct care staff. The workgroup is expected to develop recommendations, and provide a report to the Governor and Legislature by December 15, 2008. The workgroup will provide crucial information and guidance on a key aspect of the direct support worker's daily life, and thus, by extension, the quality of life of the individuals OMRDD supports.

This legislative requirement compliments OMRDD's current policy that recognizes the best way to both prevent abuse and promote richer lives is by strengthening, valuing and nourishing the relationships between individuals with developmental disabilities and the staff that support them, especially those who are deeply involved in the individuals' daily lives. Commissioner Ritter has set in motion a comprehensive initiative to ensure that the workforce has the support, competencies and policies in place to foster these relationships. More than 90,000 staff employed in state and voluntary programs will be impacted by this initiative.

Special Populations

Autism and Autism Spectrum Disorders. In 2007, OMRDD held a series of "listening forums" across the state to solicit public input regarding the OMRDD system of supports and services and to identify emerging needs. The increasing need for information and services related to autism and Autism Spectrum Disorders (ASD) was clear. In May 2008, OMRDD responded with its Autism Platform, a comprehensive plan for addressing the significant needs surrounding the dramatic increase in individuals diagnosed with ASD. The Platform describes OMRDD's planned activities related to autism as they fall into five categories. Over the next five years, OMRDD is committed to pursuing numerous initiatives in each of these areas and achieving significant enhancements in OMRDD's ability to meet the needs of New Yorkers with ASD as noted below:



- **Research.** OMRDD will continue to support its Institute for Basic Research (IBR) in undertaking a wide range of studies that examine, among other things, genetic and environmental causation, brain morphology, and the potential to develop laboratory bio-markers for early detection of ASD.
- **Translating Research into Practice.** The driving force behind OMRDD's commitment to research into the causes and manifestations of autism is the extent to which what is learned can inform the way treatment and supportive services are provided. OMRDD has identified numerous initiatives that will improve its system of supports and services for those with ASD. These initiatives include developing standardized guidelines for the screening, diagnosis and assessment of ASD, developing positive approaches for addressing challenging behaviors, bringing instruction on behavioral intervention to families, and developing state-of-the-art residential services.
- **Uniting Public, Private and Non-profit Interests.** OMRDD is committed to bringing the collective knowledge, experience and research capacity throughout NYS to bear on the quest to understand all intellectual and developmental disabilities. Pooling the energy and resources of our schools, researchers, service providers, and families will ensure leverage of the greatest progress. To this end, OMRDD will work to partner with and bring together resources wherever they exist in collaborative projects.
- **Putting People First.** OMRDD will participate in and share leadership of a new Inter-agency Task Force on Autism. This Task Force will embody the ongoing collaboration among state agencies that is aimed at Putting People First. The Commissioners of OMRDD and the State Education Department (SED), as co-chairs of the task force, will engage state agency leaders in finding ways to bring supports and services to New Yorkers with ASD more directly, efficiently, and effectively. Specifically, within this landmark commitment to inter-agency cooperation, OMRDD will work with other human service agencies to examine ways to improve early intervention services, the dissemination of information to families, implementation of applied behavioral approaches, and the transition from childhood to adult services. The inter-agency Task Force on Autism will make recommendations for cross-system improvements in these areas to the Inter-Office Coordinating Council.

In addition, OMRDD will continue its work with the SED to develop additional Children's Residential Program residences to allow more of New York's children with challenging behaviors to live and be supported at home in New York. It will work with DOH and other agencies to update best practice guidelines for early assessment and intervention for children with ASD. And, OMRDD will work with the Office of Children and Family Services (OCFS) to improve how OMRDD and OCFS coordinate services for children with ASD who are under OCFS custody.

- **Providing Information.** Over the next five years, OMRDD will seek ways to get the best available information on autism and related supports into the hands of New York families who need it. It is essential that parents, teachers and human services workers are aware of and have access to information that will help them identify and gain access to supports and services individuals with ASD need. In partnership with others, OMRDD will bring First Responder training programs to areas throughout the state and continue to bring scientists and researchers together to share information and research findings at IBR's annual Elizabeth A. Connelly Memorial Conference on Autism on Staten Island.

At the direction of Governor Paterson, OMRDD will be providing a status report regarding the progress of the Autism Platform to the Legislature with the next eighteen months.

Dual diagnosis. OMRDD plans to improve delivery of necessary clinical services to individuals with dual diagnoses. Clinics, whether they are licensed by OMRDD, DOH, or OMH, are a key provider of services to people with a diagnosis of both a mental illness and a developmental disability. Many times these clinics provide both long-term habilitative therapy services and psychiatric services to persons with developmental disabilities.

Interagency collaborative work will continue to insure clinical services are available and appropriate to meet the needs of persons who are dually diagnosed. Activities include providing technical assistance to DDSOs and to voluntary providers when they are affected by initiatives that may require reconfiguration of existing patterns of service delivery. Additional strategies reflecting the collaboration between OMRDD and OMH to better support people with developmental disabilities and mental health needs are more fully detailed in the later section on Interagency Initiatives.



On a local level, DDSOs are working with regional Mental Health and County Community Service staff to facilitate development of resources to meet the needs of individuals with dual diagnoses and challenging behaviors. One example of such collaboration is demonstrated through the Broome DDSO and Greater Binghamton Health Center (GBHC) project designed to meet the needs of the people with developmental disabilities with acute mental illness needs. This effort will help to prevent the need for more intensive services and loss of residential placement. For a number of years Broome DDSO, GBHC, and the local provider community have identified a significant unmet need to provide crisis intervention for individuals with developmental disabilities and mental health issues. To meet this need, a proposal to provide short term crisis intervention residential services is in development. This program will serve individuals in the six county area the Broome DDSO serves. The program includes two group homes located adjacent to the GBHC. Each home will serve six individuals: one for six individuals who are adolescents and one for six adults.

Jointly, Broome DDSO and the GBHC developed the proposal to include staffing, residential design, admission criteria, and services provision. The GBHC is providing twenty-four hour psychiatric coverage. The agencies are partnering to develop collaborative agreements, treatment protocols, staff training, curriculums, operating practices, and shared staff arrangements.

Older people with developmental disabilities. OMRDD's initiatives and policies related to aging are guided by the Commissioner's Task Force on Aging, which reconvened in June 2006. Membership of the Task Force represents the State Office for Aging (SOFA), DOH, Commission for Quality Care and Advocacy for Persons with Disabilities (CQCAPD), Developmental Disabilities Planning Council (DDPC), provider agencies, self-advocates, parent advocates, DDSOs, and various OMRDD Bureaus. Focus Groups held in each DDSO led the Task Force to form four sub-committees: In-Home Supports, Nursing Home Diversion and Discharge, Prevention/Geriatric Assessment/Health, and Workforce Readiness.

Accomplishments include: development of Preventive Health Care Screening Guidelines for older adults, Comprehensive Assessment Guidelines, and Health and Wellness Guidelines; planning for the development of an Aging Resource Center, with information and resources on the OMRDD website; and development of best practices in nursing home diversion and discharge to be used in curricula for training of staff and natural families.

As a result of collaborative efforts with SOFA, OMH and DOH to assist persons with developmental disabilities to successfully age with choice in the community, OMRDD sponsored a multitude of statewide videoconference training on agency resources, dementia care, individualized alternatives to nursing facility placement, and end-of-life care.

Further, OMRDD, in collaboration with SOFA, the Strong Center for Developmental Disabilities, and several provider agencies, supports the annual statewide training initiatives of the Third Age Provider's Committee, a group of non-profit providers of services to older adults with developmental disabilities. Cross-systems training planned for Fall 2008, being jointly planned with SOFA, establishes a framework for interagency contacts and collaboration between SOFA and OMRDD at the local level to support the needs of older adults with developmental disabilities and their aging caregivers.

Contacts on Aging have been established in each DDSO, and more than half of them participate in Interagency Aging Coalitions that encourage cross-agency training and sharing of aging services. OMRDD participates on the Geriatric Mental Health Council, chaired by OMH and SOFA, in an interagency effort to advance geriatric mental health care begun with the enactment of the Geriatric Mental Health Act, which took effect on April 1, 2006. Two OMRDD psychologists provided a workshop on "Mental Health throughout the Lifespan in Persons with Developmental Disabilities," for the Geriatric Mental Health Alliance at Hunter College, NYC in spring 2008. OMRDD participated in a Hospice and Palliative Care Task Force that promoted the development of cross-agency training for staff of Hospice and OMRDD. Curricula and resource materials were developed and training was delivered to several hundred participants during 2006-07.

Long standing alliances exist with SOFA, OMH, and other state and voluntary agencies that will continue to encourage future collaboration to improve service delivery and planning for persons who are aging and their families.

Children. Children account for a significant percentage of the people already served by OMRDD. The most natural setting for children is their family homes. For that reason, the overwhelming majority of OMRDD services to children are delivered at home.



OMRDD's focus on providing services for children in their own homes is in keeping with the Coordinated Children's Services Initiative (CCSI). CCSI establishes an expectation that children receive appropriate services in their homes, in their community, and from their home school district. A recent initiative undertaken by the Commissioners of all child serving agencies refocuses the delivery of services to children in accordance with the CCSI principles, cutting across agency boundaries.

An important venue for interagency coordination for children's issue is the Children's Cabinet. This Cabinet, established by the Governor, has chosen to concentrate on three priority issues related to children: access to health insurance, universal pre-kindergarten, and disconnected youth. In a multi-agency approach to increase access to Child Health Plus, OMRDD provided training to 98% of service coordinators in how to access "facilitated enrollers" in Child Health Plus and has engaged in an outreach campaign on access to health coverage for families and siblings of individuals with Medicaid served by OMRDD, to enroll not only children with developmental disabilities, but their siblings in Child Health Plus.

OMRDD is actively engaged with other child serving agencies to enhance and coordinate services for children. Over the last several months OMRDD has worked with the Office of Mental Health (OMH) as it updates its Children's Mental Health Plan (CMHP). The plan began with the creation of four workgroups to focus on the following various aspects of children's needs:

- Social and emotional issues;
- Family engagement and support, early identification, and evidence based practices;
- Workforce; and
- Accountability and systems integration.

Members of these workgroups included over 100 representatives from all NYS agencies, local governments, and providers from around the state. OMRDD was well represented on these workgroups. CMHP was presented at public forums around the state as a statewide, inter-governmental approach intended to incorporate the needs of all children in every locality in the state.

OMRDD's Advisory Council has established a sub-committee focused on the educational needs of children with developmental disabilities. The membership of this group includes family members and professionals from around the state. Amongst its accomplishments, the sub-committee has created a special education curriculum that is presented as a professional development option for service coordinators several times annually by instructors from the CQCAPD. The committee is also involved in promoting notification to children about to transition from school of the existence, access to, and specific services provided by OMRDD.

OMRDD is committed to working collaboratively to address children's cross-systems needs in order to seamlessly blend programs and services to achieve the outcome of providing complete, appropriate services regardless of the location of the child or noted disability.

Children with complex medical needs. OMRDD is responsible for three Care at Home (CAH) model waivers (CAH III, IV and VI) under authority granted by section 1915© of the Social Security Act. DOH administers these waivers in its role as the single state Medicaid agency. The OMRDD CAH waivers support 600 children.

OMRDD's CAH waivers provide for services intended to support children with developmental disabilities and complex medical conditions to live in their own homes with their families, thereby avoiding placement in Intermediate Care Facilities for People with Developmental Disabilities (ICFs/DD). Children who are enrolled in the waivers are provided with case management services, respite care, and assistive technologies/home modifications. Most importantly, the waiver authority allows children to be determined Medicaid eligible without taking into consideration the income or resources of their parents. Medicaid eligibility makes available a wide array of Medicaid State Plan services that address the complex health problems of these children.

Forensics. Within the total population of persons with developmental disabilities in NYS, there are a small percentage of individuals who have histories of significant involvement in the criminal justice system or serious offending behaviors. Some of these individuals need intensive treatment and supports from OMRDD to address the issues that are interfering with their ability to live independent, fulfilling and law abiding lives. In providing services and supports for these individuals, OMRDD strives to maintain its commitment to helping people with developmental disabilities live richer lives.



All OMRDD Intensive Treatment Programs [ITPs] (Centers for Intensive Treatment, Regional Intensive Treatment Programs, and Local Intensive Treatment Programs) provide fully individualized services for all participants, through treatment planning processes that are centered on the unique needs of the individual as well as his or her hopes, dreams, and aspirations. OMRDD encourages families and individuals with developmental disabilities to participate in these processes. In addition, OMRDD encourages individuals who reside in ITPs to participate in local and statewide self-advocacy groups, and each Intensive Treatment Program involves their local self-advocacy group in the decision-making and policy setting functions of the program.

OMRDD believes that the most effective way to manage the potential risks that these individuals pose is through a multi-level, individualized system of comprehensive assessment and risk management planning. Using the 11 Elements of Risk Management Planning as a guide, each DDSO has a local risk management planning process that assures that each high risk individual is provided with an appropriate assessment, that all potential risks are clearly identified, and that specific actions are taken to mitigate those risks. Local advisory committees and the Statewide Forensic Advisory Committee review the individualized risk management plans. This comprehensive, multi-level, comprehensive process of assessment, planning, and review assures that all people receive the individualized services and supports that they need to be successful.

Included in the ITP population are people served pursuant to the Sex Offender Management and Treatment Act (Article 10 MHL). Although such persons represent only a small percentage of the overall OMRDD population, the OMRDD strives to extend the principles of individualization, person centered planning, and self-determination to these individuals to the greatest extent possible. The field of Sex Offender Assessment and Treatment is continually evolving, and OMRDD endeavors to provide the most effective assessment and treatment available to identify and mitigate risks and enable individuals and their families to actively engage in the process of reducing recidivism. To this end, The Intensive Treatment Organization has organized a number of workgroups, comprised of professionals with specific expertise in Risk Assessment and Treatment to develop a series of Uniform Product Recommendations and Guidelines for statewide dissemination. At present, these workgroups are meeting frequently, evaluating available research, and formulating guidelines and recommendations for clinical practice with these high risk populations. In addition, licensed professionals are participating in train-the-trainer programs on specific instruments and practices, which will allow them to present state-of-the-art information and training to clinicians providing direct care in the field.

Cultural diversity. NYS is made up of very diverse communities that include individuals from many different ethnic, religious, and cultural backgrounds. OMRDD is committed to ensuring that all communities have access to the developmental disabilities service system and that individuals receive culturally appropriate services and supports.

OMRDD is also committed to supporting multicultural and emerging providers. OMRDD's Technical Assistance and Consultation Unit (TACU) was developed to assist these agencies in developing effective business practices. Most recently, this unit piloted a basic fiscal training program with multicultural and emerging agencies. The training covered the following curricula: An Overview of the OMRDD Service System, Benefits, Contract Services, Consolidated Fiscal Report Basics, CFR, Budgets and Prices, Billing, and Fiscal Reviews. In addition, stand-alone manuals were developed for each course to be used as resources after the training. The training and training materials were considered a success and now several of the courses will be offered through the OMRDD Training Catalog. The TACU has also developed and coordinated agency specific training at the request of specific agencies.

The Multicultural Provider Network has become the Multicultural and Emerging Agency Provider Council. The Council's mission is to serve in an advisory capacity to OMRDD and to support and strengthen existing and emerging agencies serving diverse communities. The Council will provide advice to the Commissioner based on its collective experiences navigating the OMRDD service system and on the needs of its constituencies (the individuals served and the agencies participating in the local networks).

OMRDD is working to develop new DDSO networks and to strengthen existing ones so that multicultural and emerging agencies can support each other at the local level. In addition to providing peer support, sharing problems and best practices, local networks will seek technical assistance and training from the DDSO and OMRDD Central Office, when needed.

Training to ensure staff competency and sensitivity with regards to cultural diversity is also a priority in

supporting people with developmental disabilities and their families. The cultural competence course that had been piloted in 2007 has now become a standard course available through the OMRDD Training Catalog. The training is available to service coordinators, supervisors, and program managers. Approximately 400 individuals attended this training since the fall of 2007. Six more classes are scheduled for the fall of 2008 and the winter of 2009. The evaluations for this course have been very positive.

The philosophy of “putting people first” not only applies to the constituents OMRDD supports and their families, but it also applies to the employees. It is essential that staff are equipped with cultural diversity awareness and competence as they interact with each other and provide services to the people OMRDD supports on a day-to-day basis. By valuing and appreciating diversity, OMRDD achieves excellence in the quality of services delivered. In order to accomplish this outcome, OMRDD has been training all state staff on building effective relationships in a diverse workplace.

Interagency Initiatives

Charged by stakeholders of the health and mental hygiene systems during the “People First” Coordinated Care Listening Forums in 2007, OMRDD, DOH, OMH, and OASAS have been striving to break down “silos” among systems of care. Collectively, the agencies have been taking steps to provide “people first” supports and services, driven by person centered, family-focused approaches that address fiscal, regulatory, policy and structural issues. This section illuminates the shared commitment, and more, by all of the agencies to ensuring that people do come first. The most recent information on the “People First” initiative may be found at http://www.omr.state.ny.us/images/hp_pf_progressreport.pdf.

Inter-Office Coordinating Council. An immediate outcome of the People First Forums was the reinvigoration of the Inter-Office Coordinating Council (IOCC), which had long been dormant. The IOCC, comprising the Commissioners of OMH, OMRDD, and OASAS, was re-established to eliminate barriers and improve coordination of services for people with disabilities. The IOCC met on August 20, 2007, at the Rensselaerville Institute. OASAS Commissioner Karen Carpenter-Palumbo, OMH Commissioner Michael Hogan, OMRDD Commissioner Diana Jones Ritter, and their key staff members attended this meeting. The commissioners agreed that the IOCC would meet regularly to address issues of an interagency nature, focusing on access and coordination of services. IOCC meetings are open to the public and are webcast.

Commissioner Carpenter-Palumbo assumed the duties of IOCC Chairperson, which will rotate among the Commissioners every two years. Each Commissioner appointed an agency coordinator for the IOCC. The Commissioners agreed that staff of the three State agencies would continue their ongoing work with the Conference of Local Mental Hygiene Directors (CLMHD) to improve and align local services planning.

The IOCC is addressing short- and long-term goals set forth in the “People First Coordinated Care Listening Forums Report.” The IOCC member agencies have asked DOH, SED, OCFS, and DDPC to serve as ad hoc members. Their involvement and input will be critical as the IOCC addresses the structural, financial, and regulatory barriers that limit access to services for people with multiple disabilities and cross-system needs.

Although it was not statutorily required, on January 18, 2008, the IOCC submitted the first annual report to the Governor and Legislature. The IOCC is meeting three times during 2008. The IOCC’s web page is available at <http://www.oasas.state.ny.us/pio/collaborate/IOCC/>.

The IOCC established the Program Committee and a Mental Hygiene Planning Committee. The Program Committee holds monthly conference calls to identify collaborative issues for the IOCC to address, develops the agenda for IOCC meetings, facilitates communication among member agencies and other State and local partners, and coordinates the preparation of the annual report. The Mental Hygiene Planning Committee, which has members from OMH, OMRDD, OASAS, and CLMHD, meets monthly to coordinate planning efforts of the three State agencies and local partners. Outcomes from the Planning Committee collaboration are outlined in further detail below.

Integrated Mental Hygiene county planning. OASAS, OMH, OMRDD, and the CLMHD are actively engaged in an integrated approach to local planning. Historically, each State Mental Hygiene agency conducted its own local services planning process, which included separate planning timetables, county planning requirements, and linkages to statewide planning and budgeting. Since its inception, the IOCC Mental Hygiene Planning Committee

agreed to uniform local services planning guidelines and a timetable that was designed to facilitate a stronger and timelier linkage to local governmental and State planning.

The Planning Committee's goal was to strengthen the service systems and promote coordinated care by better identifying and addressing local needs while improving services for those confronting addiction, gambling problems, mental illness, and developmental disabilities. The integrated approach to local planning provides for improvements in the quality of care provided to individuals and their families, and reductions in administrative burdens on State and county mental hygiene agencies by:

- Establishing a common approach to local services planning, including consistent processes, overarching themes, timetables, and connections to statewide planning and budgeting;
- Establishing a common approach to local services;
- Exploring opportunities for collaboration on local services planning efforts particularly focused on cross-system issues and the needs of persons with multiple disabilities while preserving and supporting each agency's own mission, goals, priorities, and constituencies; and
- Easing the local services planning burden on counties by creating a more uniform, efficient, and integrated planning process that reduces unnecessary duplication of effort and accommodates a more rational cross-system planning focus.

The Planning Committee developed the 2009 Local Services Plan Guidelines for Mental Hygiene Services and agreed to functionality in a web-based system designed to capture essential planning information and priorities among the three agencies. The web-based planning system originates in the OASAS Online County Planning System (CPS) and incorporates the planning requirements of OASAS, OMH, and OMRDD into a unified online system. To aid in gathering relevant cross-systems and agency-specific planning information, the Committee created a number of tools, most important among them the County Priority Outcomes Form. This new form allows counties to more effectively address cross-disability issues impacting individuals who need services from multiple systems. This represents a new approach to local planning that emphasizes cross-agency collaboration and supports the movement toward more integrated services for New Yorkers. Designed to streamline the planning process by eliminating duplicative paperwork, the system also encourages localities and State agencies to think and plan across systems.

Additionally, the OMH, OASAS, and OMRDD collaboration extended this spring to a series of training sessions on the new system for county and regional office staff. As a more integrated CPS is developed, additional planning data resources will be shared among the agencies and posted to the online system to support county planning efforts.

This integrated approach is consistent with the commitment to put the needs of individuals and families at the forefront of our service systems and exemplifies how a person centered philosophy works to ensure high-quality, individualized services for New Yorkers and their families. The approach demonstrates how cross-systems collaboration can lead to improved outcomes for individuals with multiple needs who require assistance across different systems.

Regional operations. The Mental Hygiene agencies have collaborated to identify infrastructure barriers that may limit easy access to services for people with multiple disabilities. Specific actions taken include:

- OMH operations are spread over five regions of the State and coordinated closely through the Central Office in Albany. OMRDD boundaries are being analyzed to determine whether alignment to the regional structure of OMH would enable both agencies to work more effectively in coordinating services.
- Mechanisms are in place for OMH Field Office staff to work with localities to facilitate coordinated care across the mental health, developmental disability, and chemical dependence service systems. The Field Office Directors report directly to the Executive Deputy Commissioner of Mental Health, strengthening the bridge between State and local operations.
- Recognizing the importance of collaborating with its State and local partners to improve access to services for individuals and families, OASAS' Bureau of Statewide Field Operations now reports to the agency's



Executive Deputy Commissioner. Placing OASAS Field Operations in the Executive Office improves the ability of regional staff to coordinate with OMH and OMRDD to make sure that people with multiple needs receive appropriate care.

OMH/OMRDD collaboration on dual diagnosis. In November 2007, Commissioners Hogan and Ritter held a video conference with the OMH Regional Directors and OMRDD DDSOs on issues related to dual diagnosis. The DDSOs and OMH Field Offices established collaborative teams, including managers and clinical staff, county mental health staff, and county community services personnel as deemed appropriate locally. The teams submitted their initial status reports at the end of November 2007 and a second report in March 2008. The reports include:

- Identification of team members;
- Identification of known persons with challenging service needs with an initial emphasis on, but not limited to, persons in inappropriate settings and/or who require cross-agency solutions;
- Identification of unique/successful collaborative activities or services and systems issues or barriers to effective coordination of services for persons with dual diagnosis and who are eligible to receive both OMH and OMRDD services; and
- Identification of existing collaborative models that may be appropriate for expansion or replication.

On April 14, 2008, a video conference was held with OMRDD leadership staff, DDSO point persons, managers, and clinical staff involved in the OMH/OMRDD collaborative team meetings/activities. The video conference agenda included the history of the OMH/OMRDD collaboration initiative, DDSO “go around” reports of unique/successful collaborative activities/services, and consensus determination of systemic obstacles and barriers to effective service delivery. Next steps include:

- Examining systems funding issue on dual diagnosis versus dual eligibility;
- Developing a definition of stabilization (acute versus sub-acute); and
- Developing a long-term “Best Practice” learning conference.

In addition, OMRDD and OMH will jointly host three regional training sessions on dual diagnosis targeting clinicians, Medicaid service coordinators, and program managers. The training sessions will focus on three areas: (1) navigation of the service systems, (2) best models of successful collaboration and services, and (3) clinical integration.

Most Integrated Setting Coordinating Council. The Most Integrated Setting Coordinating Council (MISCC) is a statutorily created council that is developing and implementing a plan to ensure that all people with disabilities receive services and supports appropriate to their needs in the most integrated setting. OMRDD chairs the MISCC, which comprises commissioners from ten State agencies and nine public advocates. This collaboration provides opportunities to address cross-system issues including improving mobility, employment opportunities, and access to community services for persons with disabilities. During 2008, the MISCC identified housing, transportation, and employment as top priorities for its plan. OMRDD, OMH, and OASAS participate on the Employment and Transportation Workgroups and the Housing Task Force, and DOH also participates on the Housing Task Force. All have been charged with focusing on activities, outcomes, and recommendations that foster the MISCC mission.

The MISCC Housing Task Force comprises people with developmental disabilities, representatives of non-profit and advocacy organizations, as well as entities of government whose work impacts the lives of people with disabilities. The Task Force was formed in 2007 to support the MISCC’s goal of ensuring that people of all ages with disabilities are afforded the choice and empowerment to live in the most integrated setting that meets their individual needs and preferences. The Task Force goals are to:

- Increase opportunities for people with disabilities to live independently in the setting of their choice and, where appropriate, with supportive services that are designed around the needs and desires of the individual;
- Define the need for affordable and accessible housing in NYS, as well as a continuum of supportive services that foster independence and choice;

- Increase awareness through a public communication and marketing campaign, as well as training opportunities; and
- Recommend to the Governor a policy agenda that furthers the collective goals of both MISCC and the Task Force.

The Transportation Workgroup, chaired by the Department of Transportation, is preparing recommendations to improve and coordinate transportation opportunities for persons with disabilities that help to facilitate their community integration. The Workgroup plans to address barriers to transportation and to research, evaluate, and provide examples of best practices for transportation policies and programs for people with disabilities.

The Employment Workgroup, chaired by the Office of Vocational and Educational Services for Individuals with Disabilities (VESID), addresses employment challenges for people with disabilities and provides legislative or policy recommendations to enhance employment opportunities. The lack of employment opportunities for people with disabilities is a substantial public policy concern. Employment is essential for people with disabilities because it enables them to fully participate in society.

The employment and transportation workgroups will work together to address transportation barriers to employment and to find better ways of providing services in the most integrated setting.

Children's Mental Health Act. The Children's Mental Health Act sent a unifying call to action to families, providers, advocates, communities, and policymakers that the social emotional development of children is a priority. This legislation established mental health as an essential component of children's health and wellness. In addition, NYS made a strong commitment to strengthening the emotional health of children by putting forth the Achieving the Promise initiative in 2006. These endeavors reflect statewide, shared concerns about the social emotional development of children. To achieve the goals set forth in each initiative, individuals representing perspectives and expertise came together in December 2007 to focus on developing broad recommendations to guide the care of children and families in New York. Those represented included parent/caregivers, youth, educators, community leaders, children/youth development experts, service providers, advocates, and policymakers from multiple State agencies.

OMRDD, OASAS, OMH and DOH staff participated in workgroups established to develop recommendations for promoting mental health and wellness of children, youth, and families. Priority issues addressed by the committees included social emotional needs of children; workforce; early identification, family support, and evidence-based treatment; and accountability and systems integration for children with multiple disability needs. Participants on the four committees, as well as a youth advisory workgroup, represented more than 100 people from all parts of the services systems, State agencies, counties, providers, associations, families, and youth.

OMH recently shared detailed recommendations during a number of public forums held around the State. Notably, one of the recommendations of the Social Emotional Development Workgroup is to facilitate continued joint efforts among OMH, OMRDD, OASAS, SED, OCFS, DOH, and other child-serving systems to help guide implementation of social emotional development and learning across the State, based on the best scientific evidence available. Participation on these workgroups has enabled each agency as well as multiple stakeholders to broaden their scope and ability to positively impact on the mental health and wellness of individuals at an early age and establish collaborative relationships.

Fetal Alcohol Spectrum Disorders. OMRDD has joined the Interagency Taskforce on Fetal Alcohol Spectrum Disorders (FASD), co-chaired by the OCFS and the Council on Children and Families (CCF), as part of an effort to ensure recognition, availability, and delivery of needed services for people who may require coordinated services from different agencies. The NY State Interagency Taskforce was established as one outcome of the federally-mandated national initiative to address the growing need for public and professional education and training, and the establishment of clinical diagnostic guidelines, which were issued in July 2004. This interagency workgroup has brought together several of New York's state agencies to address the need for prevention and intervention information about FASD through interagency collaboration and coordination. There are four Taskforce subcommittees: Education and Awareness, Prevention and Prenatal Screening, Diagnosis and Screening of Children, and Interventions and Treatment Services.



In collaboration with OASAS, OCFS, DOH, OMH, and DDPC, OMRDD participates in the work of identifying and implementing the most effective educational, preventive, and clinical services related to FASD and other conditions resulting from prenatal exposure to alcohol. Through regularly scheduled meetings together in subcommittees, and with the steering committee for the Taskforce, representatives of the member agencies share information on agency services, report on progress made in subcommittee goals and objectives, and cross-fertilize creative approaches to active outreach, education, and availability of individualized referrals and services. OMRDD continues to make videoconference trainings by OASAS available to employees statewide, through the Education and Training catalogue. OMRDD is also represented on the Taskforce Interventions and Treatment Subcommittee, whose current goal is to identify “best practices” in clinical interventions provided across the lifespan for individuals with FASD. The short-term goals of this sub-committee are to: identify best practices and ways to disseminate this information; assess the capacity of the state’s service systems to provide needed services; and assess and recommend a response to work force training needs. The long-term goal of the sub-committee is to address interagency barriers to an effective response to FASD in terms of state agency financial support and identify sources of non-public funding.

Partnership with the Developmental Disabilities Planning Council. The longstanding partnership between OMRDD and the DDPC on behalf of persons with developmental disabilities has facilitated the testing of a broad range of cutting-edge approaches and initiatives in the field. Many of these have resulted in significant changes in the design and delivery of services to individuals, and in the organization and management of service providers. Some of these initiatives grow out of OMRDD’s participation on the NYS Developmental Disabilities Network, which also includes the CQCAPD and the state’s three University Centers for Excellence in Developmental Disabilities. Most, however, originate in the DDPC’s three standing committees, which collectively seek to push the envelope in regard to supports and services for New Yorker’s with developmental disabilities. Key initiatives related to OMRDD priorities include transportation, telemedicine, and transition of youth from pediatric care to adult health care providers.

The DDPC has funded several collaborative projects to increase public transportation options that will enable individuals with disabilities to gain and maintain employment. DDSOs and provider agencies have participated in these coalitions. OMRDD is fully supportive of these DDPC activities and hopes to learn from the outcomes.

The In-Home Supports Sub-committee of the OMRDD Commissioner’s Task Force on Aging recommended that telemedicine be explored as a means of making health monitoring and medical consultation readily available to aging individuals with medical needs in OMRDD residential settings. The DDPC responded to this recommendation by releasing a request for proposals and granting funding to an OMRDD provider agency for a telemedicine demonstration project.

Initiated under a DDPC grant to SUNY Upstate Medical University, a health care transition project has focused on assisting youth and young adults with developmental disabilities and their families to prepare for and complete the transition from pediatric care to adult health care providers. The thrust of the project is to develop statewide expertise through the development and dissemination of tools that will help transitioning youth to understand their health care needs and gain competence in managing their own health care as adults. Additional funding from the DOH has allowed testing of the curriculum, which has been undertaken in collaboration with several of OMRDD’s DDSOs. Work is also underway with the Central NY DDSO to develop training that will assist transitioning youth to find and work effectively with Medicaid service coordinators to manage their own health care needs.

Medicaid

Beginning in early 2007, CMS of the federal Department of Health and Human Services began issuing rules that affect the states’ operation and financing of their Medicaid programs. In addition to basic health care, these programs make available a range of services for persons who are Medicaid eligible by virtue of low income and/or disability. OMRDD’s system of supports and services relies heavily on the federal/State Medicaid partnership to fulfill its mission to help individuals with developmental disabilities lead richer lives, in the home of their choice, enjoying relationships with friends and family in good health.

Thus far, CMS has issued seven rules that have the potential for significant negative impact on states’ ability to meet the special needs of individuals with disabilities, including those with developmental disabilities.



Congressional action has postponed the effective dates of six of the seven rules; however this moratorium is only a temporary delay and all the rules remain of concern to the states and to OMRDD.

The following are brief explanations of the rules that are of most concern to OMRDD:

- **Government Provider Cost Limit.** The Government Provider Cost Limit was published in January 2007, and is currently under Congressional moratorium until April 1, 2009. This rule will place strict limits on Medicaid payments to government providers of health care services to beneficiaries. This rule will prohibit government providers from using certain types of rate setting reimbursement systems.
- **Targeted Case Management.** OMRDD operates and oversees a Targeted Case Management (TCM) program for persons with developmental disabilities. This program, called Medicaid Service Coordination (MSC) serves approximately 70,000 individuals and families. CMS published an interim final rule regarding TCM Services on December 4, 2007. The rule is currently under moratorium through April 1, 2009. The provisions of this rule will have an impact on the kinds of services that Medicaid Service Coordinators can provide. It will require significant changes to administrative and billing processes and will result in a reduction in federal funding for this service.
- **Rehabilitation Services.** OMRDD provides community clinic and day treatment services to approximately 28,000 individuals with developmental disabilities. CMS proposed a rule August 13, 2007, that redefines a lengthy list of currently eligible Medicaid rehabilitative services as no longer reimbursable in a clinic setting. This rule would prohibit habilitation services for persons with developmental disabilities outside of ICFs/MR and Home and Community Based Services (HCBS) waiver programs. The rehabilitation services rule is currently under moratorium through April 1, 2009.
- **Outpatient Clinics.** CMS published a rule on September 28, 2007, Clarification of Outpatient Clinic and Hospital Facility Definition and Upper Payment Limit. This requires the upper payment limit calculation for these programs to be limited to what Medicare would reimburse for these services. As Medicare does not reimburse “maintenance therapies” (i.e., clinical habilitation), the upper payment limit would be zero. This proposed rule is not under moratorium.

Public Information and Outreach

OMRDD Office of Consumer Affairs. In keeping with the motto of Putting People First Commissioner Ritter created the Office of Advocacy Services. Advocacy Services is the Central Office portal to access information, supports and services provided by OMRDD. To facilitate statewide access, a toll-free Information Line was also established (Voice: 1-866-946-9733, TTY: 1-866-933-4889). The Advocacy Office advances OMRDD’s vision for people with disabilities.

The Information Line is designed to help people get answers to questions regarding supports and services for individuals with developmental disabilities. This toll free line is equipped with InterpreTALK, a telephonic interpreting service. Callers, regardless of what language they speak, are able to communicate their questions or concerns without delay.

Advocacy Services works in partnership with the Self Advocacy Association of NYS ensuring they have input regarding supports and services. The voices of our self advocates are vital as we develop more person centered, self-directed supports and services.

The Office of Advocacy Services works with individuals and their families to share information on access to services, provides another avenue to make a complaint about care and treatment, and seeks to foster a system of supports that honors an individual’s right to be independent and responsible for their own life.

Public Information. The work of the Office of Public Information is driven by the mission and vision of the agency, and works to support the Commissioner’s initiatives.

In late 2007, OMRDD began to revamp its look and mission to inform about its more person centered, people-driven mission and principles. This consisted of not only refreshing the agency’s mission, but creating branded brochures and other communication tools. A strong brand is an invaluable tool that will assist OMRDD in

delivering its message more clearly, connecting with the individuals and families it serves, as well as the general public, and one that takes in the wants and needs of the individuals with developmental disabilities and the public. Recently OMRDD announced its new web site and internal Intranet for employees to deliver transformational agenda messages. Stories of Success and Everyday Heroes are showcased as evidence of real life accomplishments.

In 2008, the Office of Public Information began working in partnership with agency leadership and the SUNY Albany School of Social Welfare on an aggressive Direct Support Initiative, which involves a three-pronged approach to preventing abuse and neglect. Public Information began working on public and internal awareness campaigns that will facilitate communications with employees, and will also provide prevention and education tools aimed at creating public awareness about abuse prevention. This initiative is intended to promote a culture that is not tolerant of abuse and neglect, and to target reduction of stressors that can create situations potentially leading to abuse and neglect. The outcome is a culture that supports and protects not only the individuals in its care, but those employed as caregivers. This is discussed in greater detail in Chapters 7 and 9.

The Office of Public Information also intends to support the Employment First workforce initiative by sponsoring a yearly event in celebration of National Disability Employment Awareness, with the first ever targeted for October 2008. The Employment First initiative is further outlined in the employment section of Chapter 6.

Crisis Intervention

Families often do not know where to turn in a time of crisis or when faced with the challenging behaviors of a loved one with developmental disabilities. Sometimes the only option in a crisis situation is a costly out-of-home residential opportunity, a solution that does not serve the family well and may be fiscally imprudent. Family Support Services (FSS) can help families in times of crisis when a family member or loved one becomes ill, or when other difficulties arise. With this assistance and support at the time of a crisis, families often work through these situations and the family unit can be maintained.

OMRDD, OMH, OASAS, DOH, and OCFS staff members have participated in the Restraint and Crisis Intervention Committee, along with provider organizations, mental health professionals, and family members. This Committee was established by Chapter 624 of the Laws of 2006 and now extended by Chapter 470 of the Laws of 2008 to examine crisis intervention approaches used by several State agencies to identify the most effective, least restrictive, and safest techniques for the modification of a child's behavior in response to an actual or perceived threat by the child of harm or bodily injury to the child or others; review models of crisis prevention and intervention, including the use of physical restraints; and establish uniform and coordinated standards giving preference to the least restrictive alternative for the use of such techniques. The Committee issued a report in September 2007. OMRDD is modifying its curriculum Strategies for Crisis Intervention and Prevention—Revised and developing new regulations related to behavior management to incorporate Committee recommendations. The Committee will continue to report annually on the progress of its 2007 recommendations, as well as any new recommendations.

Access to Services

Enhancing access to services is a cornerstone of OMRDD's vision, values, and mission. A key aspect of this is strengthening the role and authority of DDSOs for service development, decision-making and resource management. This began with the de-centralization of projects initially funded in the Options for People Through Services (OPTS) program, and continues with the establishment of local practices that involve the widest cross-section of stakeholders in open, transparent, and equitable processes. The intent is to address local priorities through Putting People First principles, and encouraging innovative, cost-effective, individualized services and supports. This over-arching process applies to all OMRDD programs and services regardless of funding source and whether they are State-operated or sponsored by voluntary agencies.

The important hallmarks which underpin greater access to services include:

Inclusion and equity. DDSO processes are broadly inclusive. Multiple stakeholders such as families, individuals, self-advocates, local governments, and providers are invited to plan and identify needs, rank priorities, review proposals, and recommend funding. In appropriate geographic areas, efforts to reach under-served communities and include new and emerging service providers are OMRDD priorities.



Balancing State and local priorities. Local issues are recognized through local government planning, public forums, service registration, surveys, and other means to elicit and generate needs and ideas. These are coupled with articulated statewide OMRDD priorities which may include a variety of cross-State agency concerns such as children's services, health issues, and housing needs. Together, State and local priorities yield a finely balanced program which must be implemented at the DDSO level.

Timeliness and transparency. Access to services is effective only when processes are widely and commonly known and understood by the public, and decisions are timely and responsive. Maximum efforts to educate the public about available services, publish and distribute service applications, and involve stakeholders in decision-making are the cornerstone of DDSO systems. These processes are intended to be and must be seen as open, fair, and unbiased. Also, timeframes to review and decide on service requests must be rational and responsive, and understood by all participants, and provide opportunities for feedback.

Taken together, these efforts to enhance access to services build an OMRDD system which more closely links a broad array of supports for the families and individuals who need them the most. It also demonstrates that OMRDD welcomes participation by all who have a stake in improving services for persons with developmental disabilities.

On another note, with the increasing recognition and identification of the Autism Spectrum Disorders (ASDs), the professional community has recognized the need for the identification and use of scientifically valid, standardized, and consistent practices in the screening, assessment, and diagnosis of these conditions. For individuals who seek eligibility for and access to specialized services through OMRDD, the effort to ensure timely access to such services will be supported by encouraging the use of such individualized assessment processes that are evidence-based and recognized for their excellence as professional 'best practices' for the diagnosis of ASDs. In response to the increased need for consistent implementation of reliable and scientifically validated screening, assessment, and diagnostic practices, OMRDD has also initiated the establishment of an Autism Workgroup. The purpose of the Workgroup is to research, review, and update recognized best practices and assessment tools for the identification of ASDs, ultimately for inclusion in a set of Best Practice Guidelines. These established Guidelines will be available for use by OMRDD, its community providers, and referring professionals in the community. Scientists and clinicians with expertise in the ASDs have been recruited for this Workgroup; members include individuals from OMRDD facilities, and from public and private university and clinical settings, both within and outside NYS. Members will participate on development and expert review panels, and produce a Best Practices document that can be made available in print and on the agency website.

Coordination of Services

Service coordination assists persons with developmental disabilities and their families in gaining access to services and supports appropriate to their needs. OMRDD delivers almost all service coordination through its 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).

MSC provides a vital link to information and service options. It is the role of the service coordinator to work with people and their families to develop a plan of care that assures individuals eligible for services through OMRDD receive the assistance they need. As of 2008, more than 74,000 New Yorkers are benefiting from OMRDD's MSC program. Service coordinators are employed by the DDSOs and by the more than 440 MSC vendors statewide.

To keep service coordination staff and service coordination providers informed about program changes, new programs, best practices, training opportunities, and other information relevant to the provision of quality service coordination, in late 2005, OMRDD instituted an MSC Electronic Advisory (E-Visory). The MSC E-Visory is sent out via OMRDD's webmail system to approximately 1,400 MSC Supervisors, DDSO/Executive Directors, MSC Program Managers, the provider associations, the Self Advocacy Association, the Willowbrook Task Force Subcommittee on Service Coordination, and other interested parties. To date, 64 issues of the MSC E-Visory have been distributed statewide. It is expected that OMRDD will continue to distribute issues of the MSC E-Visory on a regular and timely basis during the next five years.

The MSC Vendor Manual, the official compendium of rules and procedures, is now available on OMRDD's website. It is updated yearly to provide the most current information related to MSC to service coordinators, supervisors, program administration, individuals served, their families, and advocates.



Individuals with developmental disabilities have the right to choose their MSC provider and service coordinator. In 2007, OMRDD implemented a survey to assess the reality of choice. The survey results showed that individuals are, to every extent possible, given choices but the reality is that there are times that the agency and/or service coordinator chosen are not available. This is usually due to the agency's inability to serve the person (e.g., at capacity, lack skills to work with a specific population) and/or the specific service coordinator does not have an opening on his/her caseload and therefore, cannot serve the person at the time the service is requested.

In late 2005, OMRDD implemented a survey to better understand MSC service coordinator retention issues and recruitment best practices. The survey results were analyzed and a final report was issued in November 2007 to all MSC vendors who completed the survey, the Provider Associations, and DDSO Directors. Based on the survey, two of the major themes identified that impact on the retention and recruitment of MSC service coordinators were training and supervision.

During 2008, the two major themes identified in the retention survey prompted OMRDD to emphasize the need to provide regular, quality training to new and seasoned MSC service coordinators and to MSC Supervisors. To this end, training consortiums were developed in every DDSO catchment area. The consortiums consist of MSC and training staff from the DDSOs and MSC provider agencies. They meet on a regular basis. Utilizing funds provided to each DDSO in a specially designated MSC training budget, the consortiums have sponsored MSC forums to train as well as honor service coordinators and supervisors for their worthwhile efforts. In addition, several MSC Supervisors Leadership Institutes have been held in various parts of the State.

Train-the-trainer sessions for the Core curriculum and the required MSC courses continue to be held statewide to develop more qualified instructors and to help eliminate the postponement or cancellation of these courses. Also, several new courses were developed and are now offered on a regular basis in OMRDD's Training and Development Catalog. These include Cultural Competence, Start to Finish: Steps to Successful Special Education Services, and The Next Step: Transition Services. A new course entitled Navigating Two Systems, which focuses on individuals with dual diagnoses in need of services from both OMRDD and OMH, was piloted in spring 2008 and will be offered statewide in 2009.

Implemented in 2004, MSC Supervisors Videoconferences are held four times every year in March, June, September, and December. Each videoconference is broadcast to over 20 sites statewide to approximately 300 MSC Supervisors. The sessions have provided vital information on topics such as Medicare Part D, Eligibility, ISP changes, MSC program changes, Child Health Plus, as well as panel presentations on time management, supervision tips, and parent/family expectations and relationships with MSC service coordinators

One of the new initiatives for MSC is the implementation of computer technology to assist service coordinators with managing and reducing paperwork. Since 2006, every DDSO service coordinator was provided with a laptop computer and voluntary agencies were encouraged to purchase laptop computers for their service coordinators. To allow service coordinators to electronically complete and distribute ISPs, monthly notes and other required MSC documentation, the development of an MSC Electronic Record was initiated as part of the Real Choice Systems Change Grant. The goal is to electronically connect DDSO and voluntary agency service coordinators to OMRDD, other State agencies, individuals, families, and advocates for more timely processing and distribution of MSC documents as well as for monitoring, claiming, and billing purposes.

Charged with developing a definition of "informed choice" by OMRDD's Executive Deputy Commissioner, the Informed Choice Design Team was formed in May 2007. The team will also recommend, as necessary, changes to the service coordination program and the impact of this on other services based on the application of informed choice. As of July 2008, the design team had crafted a draft definition of informed choice that is being readied for review by OMRDD's senior management. The design process includes input from experts, including parents, advocates, the Willowbrook Task Force, and Provider Associations prior to implementation of any change.

The Institute for Basic Research in Developmental Disabilities

The Institute for Basic Research in Developmental Disabilities (IBR) is the research arm of OMRDD. Located in Staten Island, NY, IBR conducts internationally recognized basic and clinical research into the causes and prevention of developmental disabilities. It also provides biomedical, psychological, and laboratory services to individuals with developmental disabilities and their families, and conducts public and professional education programs.

IBR's research program currently consists of seven departments and 45 laboratories. Service programs include the George A. Jervis Clinic, a tertiary-level diagnostic and research clinic; the Specialty Clinical Laboratories, which conduct specialty medical laboratory testing for a variety of genetic, metabolic, and neurodegenerative disorders; and the Comprehensive Genetic Disease Program at Richmond County, which provides genetic testing and genetic counseling services. Among the Institute's educational activities is a graduate studies program entitled the Center for Developmental Neuroscience and Developmental Disabilities, which is conducted in collaboration with the City University of New York.

IBR serves New Yorkers with developmental disabilities and their families. IBR furthers the goals of OMRDD by:

- Conducting research into the causes and manifestations of developmental disabilities;
- Developing methods to improve the diagnosis, prevention, and treatment of developmental disabilities;
- Providing specialized biomedical, psychological, and laboratory services to individuals with developmental disabilities and their families; and
- Educating the public and professionals regarding the causes, diagnosis, prevention, and treatment of developmental disabilities.

The goals of IBR's research on developmental disabilities are to prevent developmental disabilities and to improve the quality of life of affected individuals and their families in the State through an integrative approach that combines new advances in genetics, neuroscience, the behavioral sciences, and clinical science. IBR will apply these advances to identify the causes of autism and ASDs, and to evaluate therapeutic interventions in autism and in better-understood disabilities such as Down syndrome and Fragile X syndrome. IBR will disseminate research findings and will extend service and education programs through organized outreach activities.

Current Major Projects.

- NYS Autism Consortium—IBR is spearheading the development of a NYS consortium of organizations with expertise in ASDs. The consortium will bring together academic and research facilities, program providers, parents, advocates and educators to pursue large-scale federal and private funding for extensive and ongoing collaborative research into the causes and treatment of autism, to undertake seminal research projects, and to translate research into state-of-the-art training and practice in serving individuals. The Consortium was discussed in greater detail earlier in this Chapter under Special Populations.
- Department of Defense-funded study of brain in autism—In April 2008, IBR received a \$1.9 million grant from the U.S. Department of Defense Autism Spectrum Disorders Research Program to study correlations between structural and biochemical abnormalities in the brain in autism and the clinical symptoms of the disease.
- International Brain and Tissue Bank for Autism—Plans are under way to make IBR the site of the one international brain and tissue bank for autism when the National Alliance for Autism Research, Autism Speaks Autism Tissue Program is moved to IBR. The bank will receive tissue from all over the United States, and for the first time in the autism community, create a collection of non-brain tissue, including neuronal progenitor cells. As a unique resource, the bank will become a training center for neuropathologists who wish to work in the field of autism.
- Asperger's Disorder Behavior Inventory—IBR researchers are developing the Asperger's Disorder Behavior Inventory, which will provide quantitative, age-standardized scores for behavior relevant to children ages 2–12 with Asperger's disorder.
- NYC Early Intervention Contract—IBR has been awarded a contract by the NYC Department of Health and Mental Hygiene (DOHMH) to provide early intervention evaluations and initial service coordination on a fee-for-service basis. Expected to start up in September, the program will help fill a gap in NYC for early intervention evaluation services and will identify children to participate in IBR research studies.
- Behavioral Assessment and Intervention Program—IBR, SED and VESID are currently developing a Behavioral Assessment and Intervention Program to begin in January 2009 within the five boroughs of NYC. Behavioral specialists will provide intensive individualized functional behavioral assessment and



intervention for students with developmental disabilities who are experiencing severe behavior problems. Teachers, staff, and caregivers will also receive support and training that will allow them to work with students within the school setting and avert the need for more intensive treatment and crisis placement. The program is intensive and individualized and will make use of the most current research-based methods of assessment and behavioral interventions.

Success and Contributions. Scientists at IBR have developed an international reputation for their discoveries that help prevent developmental disabilities. Recent advances and initiatives include:

- Autism susceptibility genes—Employing both proteomics and genomics approaches, a group at IBR has discovered new autism susceptibility genes that may be critical in the development of autism.
- PDD Behavior Inventory—IBR researchers have developed an important new assessment tool for children with autism, the PDD Behavior Inventory. It is now being used by over 30 different research centers and has been published commercially for widespread distribution.
- Fragile X syndrome—Scientists at IBR demonstrated a 50% reduction in receptors for the inhibitory neurotransmitter, GABA, in the brain of the fragile X mouse, which helps explain the susceptibility to seizures and hyperactivity of human subjects with fragile X. IBR researchers are developing a new monoclonal antibody assay (up to 1000-fold more sensitive than the currently available test) for direct quantization of the Fragile X protein. Because this test will be much less expensive than currently available tests, it should allow for Fragile X syndrome to be included in newborn screening panels.
- Dementia—A large-scale project by IBR researchers on aging in individuals in NYS with intellectual disability with and without Down syndrome has shown that genotype (ApoE), cholesterol levels, and estrogen levels (in women) are strong predictors of the development of dementia.
- Batten disease—An IBR physician-researcher conducted a trial that demonstrated the beneficial effects of Cystagon treatment in individuals with Batten’s disease.
- Person centered planning—An IBR researcher has published and disseminated widely a book on person centered planning and a well-received health and well-being curriculum for adults with developmental disabilities.
- Intellectual disability gene—An Institute scientist cloned, characterized, and obtained official Human Genome Organization (HUGO) recognition for a new gene (HSD17B10) that is important for normal brain function and, when mutated, causes severe intellectual disabilities.
- Cerebrolysin—An investigator at IBR discovered that a novel substance, Cerebrolysin, which has been shown experimentally to enhance learning and memory, contains an active substance (CNTF), which induces neurogenesis and neuronal maturation.
- Autism brain bank and atlas—A laboratory at IBR has become the repository for Autism Speaks’ Autism Brain Bank project and is coordinating the production of a detailed autism brain atlas.
- Autism conferences—IBR scientists have hosted successful international conferences at the institute to explore the role of oxidative stress in autism, and prenatal/ perinatal issues in autism.
- High-risk infant study— An IBR researcher received NIH funding to expand her ongoing research to a program project to study a large group of babies admitted to neonatal intensive care units (NICUs) who are at high risk for developmental disabilities. Recently, this program identified increased autism rates in infants who had been in NICUs.
- Aggression biomarkers study— Working with staff from the OMRDD DDSOs, IBR clinician-researchers have undertaken a survey to determine the degree and prevalence of aggressive and self-abusive behaviors in individuals with developmental disabilities. Preliminary analyses of data indicate that 40–50% of subjects have aggressive behavior.



Incident Notification and Access to Records

Chapters 24 and 271 of the Laws of 2007, and more recently Chapter 321 of 2008, include requirements regarding notification of incidents and access to records pertaining to allegations of abuse and neglect. OMRDD engaged in extensive collaboration during the development of regulations and guidance documents related to implementation of the law. This was done to ensure consistent interpretation of statutory language and that differences in implementation by each affected agency were appropriate and based on either systemic differences, differences in the individuals served by each system, or differences in other legal underpinnings (e.g., applicable federal regulations).

The Task Force on Mental Hygiene Records plays an important role in records access. The Task Force is chaired by OMRDD Commissioner Diana Jones Ritter and includes representatives from OMH, CQCAPD, OCFS, SED, DOH, provider agencies, labor organizations, and parents and individuals receiving services.

The Task Force met from January to March 2008 and issued a report in April 2008. Task Force discussion and deliberation centered on the following areas:

- Improving communication between providers and families;
- Reporting of suspected abuse;
- Developing guidance for the redaction of records;
- Developing a procedure for administrative review of denial of records under the Law related to notification of incidents and access to records; and
- Assuring consistency in implementing the recently enacted law among providers and State agencies.

The following are the Task Force's recommendations:

- Direct OMRDD, OMH, and OASAS to develop curricula aimed at enhancing relationships and communications amongst staff, individuals who are served, families, and advocates.
- Develop informational pamphlets describing specific agency rules regarding access to records, requirements, and responsibilities when responding to an incident or allegation of abuse.
- Take necessary steps to re-train staff in reporting requirements to emphasize to staff members their continuing obligation to report incidents and allegations of abuse with the enactment of this Law.
- Develop guidelines to maximize consistency of redaction so that it is done in the spirit of meaningful disclosure, while complying with the law's requirement of redacting the names of employees and individuals receiving services in order to protect their privacy rights.
- Establish an administrative appeal process for individuals who have been denied records and documents related to incidents and allegations of abuse.
- Direct OMRDD, OMH, OASAS, and CQCAPD to work together to develop consistent guidance, where appropriate, on the implementation of the law.

Regulatory Initiatives

Behavior management regulations. OMRDD has been developing regulations on behavior management for many years. For various reasons the regulations were never formally finalized. These regulations address many areas, including: functional assessment, development of behavior management plans, the use of personal intervention techniques (i.e. manual or physical holds as taught in the SCIP-R curriculum), the use of mechanical restraining devices, the use of time-out rooms, the use of medications to modify or control behavior, and aversive conditioning. In 1994, OMRDD published proposed behavior management regulations in the State Register but was unable to finalize those regulations due to controversy surrounding aversive conditioning.

More recently, an internal Central Office workgroup was convened to recommence work on the behavior management regulations and has been meeting frequently to develop a new draft. At the same time, workgroup members have been actively involved in related projects which have strongly overlapping issues that affect the content of the regulations. These include revisions to the SCIP-R curriculum and participation on the Interagency



Restraint and Crisis Intervention Techniques Committee. A new draft of NYCRR 633.16 is nearing completion and will be shared with stakeholders from the DDSOs and voluntary providers for review and input.

The overall goal of establishing formal behavior management regulations is to assure that for those individuals who present with challenging behaviors requiring intervention, clear standards are identified that underscore the importance of a comprehensive approach to behavior support and management and focus on prevention and early intervention at its core. Some key changes to the new draft behavior management regulations reflect the commitment the agency has made to increase the use of positive behavior supports, identify the most effective and least restrictive or intrusive intervention techniques for the modification of an individuals' challenging behaviors, and reduce reliance on the use of physical interventions while at the same time increasing monitoring, safeguarding, and oversight of plans that include such interventions. These changes also reflect the agencies mission to deliver person first services in the most integrated settings possible.

Incident and abuse regulations. OMRDD plans to revise its existing regulations related to incident and abuse. Among other needed updates, the regulatory project would clarify its application to non-certified supports and services, and clarify the responsibility of providers to intervene when familial abuse is alleged. The new regulations will also incorporate new statutory requirements for notification and access to records.

Medication administration regulations. OMRDD plans to update its Medication Administration regulations as the current regulation is outdated and needs several amendments. These include new and/or revised standards for: nursing supervision, controlled substances, off-site administration, storage of medications including syringes and needles, medication regimen reviews, access, staff certification, pre-pour and med bars, medication errors, and emergency medication. The regulations also need to be amended to include a new "independent self-medication management" category for persons served, and a glossary pertinent to medication administration only.

Outcomes and Performance Measures

The following outcomes and performance measures have been developed to define the key focus areas for work activities related to supports, services, functions or workforce that impact across all facets of people's lives.

Outcome:

Improve the capacity of OMRDD and its providers to maintain a qualified workforce that supports individuals with developmental disabilities and their families.

Performance Measure:

- Decrease in the statewide turnover rate of direct care professionals employed by provider agencies and OMRDD.
- Creation of a direct support professional advisory process related to workforce recruitment and retention.

Outcome:

The frontline workforce, including supervisors and those who serve self-directing individuals, will have access to ongoing, structured, professionally delivered, competency-based training in an effort to increase job performance and satisfaction, as well as the quality of care provided to individuals with developmental disabilities.

Performance Measure:

- Development of and provision of enhanced training programs statewide.
- Increase in level of positive feedback related to direct support professional and supervisor trainings.
- Increase in reported job satisfaction for direct support staff and supervisors.

Outcome:

OMRDD will recruit and retain highly skilled professional clinicians to enhance the quality of services provided for individuals with developmental disabilities.



Performance Measure:

- Decrease in the rate of clinical staff turnover.
- Development of recruitment strategies to increase the interest of clinicians in employment within the OMRDD provider network.

Outcome:

Enhance design of the Medicaid Service Coordination program to ensure consistent provision of service to individuals with developmental disabilities and their families.

Performance measures:

- Increase in the effectiveness and quality of service coordination as measured by service satisfaction.
- Decrease in the turnover rate of Service Coordinators.

Outcome:

Fully integrate the importance of the concept of informed choice as a basic right into OMRDD service designs and services delivery.

Performance Measure:

- Increase in the percentage of favorable responses to NCI Consumer Survey indicators related to choice.

Outcome:

OMRDD and its providers will have an improved capacity to offer supports for crisis intervention to individuals with developmental disabilities who live at home with their families.

Performance Measure:

- Increase in the percentage of families reporting satisfaction with access to supports and services when needed.

Outcome:

People who are aging with developmental disabilities, their caregivers, OMRDD employees, providers, and the general public will have more access to information about OMRDD services and supports to improve services for persons who are aging.

Performance Measure:

- Development of a web-based Aging Resource Center which will be a clearing house for various curricula, related links, and best practices.
- Positive satisfaction assessment of Aging Resource Center to assure functionality and utility.

Outcome:

OMRDD and SOFA will establish a framework for interagency contacts and collaboration between the two agencies at the local level to support the needs of older adults with developmental disabilities and their caregivers.

Performance Measure:

- Development of coordinated directories on service providers, resources, and contacts at the local level from DDSOs and their respective counterparts in the Area Agencies on Aging (AAAs).



- Positive satisfaction assessment of aging resource directories by staff, caregivers, and people with developmental disabilities who are aging.

Outcome:

Initiatives will be implemented to increase awareness of Fetal Alcohol Syndrome (FAS), its potential effects, and clinical resources for treatment for both individuals who seek or receive services from OMRDD, their service providers, and for members of the OMRDD workforce.

Performance measures:

- Development of resource documents and tools.
- Distribution of information through various media statewide.

Outcome:

Transportation opportunities that facilitate community integration for people with developmental disabilities will be improved.

Performance Measure:

- Increase in the percentage of people reporting access to transportation when they need it.

Outcome:

Young adults with developmental disabilities will transition from pediatric care into the adult health care system in a timely manner.

Performance Measure:

- Increase in the number of young adults with developmental disabilities who express satisfaction with health and medical services.

Outcome:

OMRDD will advance its understanding of autism and state-of-the-art services and treatment protocols for individuals with ASD and improve its capacity to offer these types of services to individuals that it supports.

Performance Measures:

- Establishment of a program for intensive, but short term, assessment, treatment and stabilization for adults with autism spectrum disorder who are experiencing crises.
- Development of standardized guidelines for the screening, diagnosis and assessment of autism spectrum disorder in support of OMRDD eligibility determinations.
- Establishment of a voluntary autism registry to improve epidemiological understanding of ASD.
- Establishment of a statewide, cross-discipline autism educational institute to improve practitioners' ability to accurately assess and diagnose ASD.
- Pilot of additional clinical internship programs with NYS universities.
- Establishment of an Interagency Task Force on Autism.
- Development of and distribution of, through various media, a statewide resource directory and regional resource guides.
- Provision of training in the use and implementation of established Best Practice Guidelines for the assessment of autistic spectrum disorders.

**Outcome:**

Enhance services for individuals who have a dual diagnosis of mental illness and developmental disability through the development of collaborative agreements with OMH.

Performance Measure:

- Development of simplified mechanisms for people who have complex and multiple needs to access supports and services.
- Development of curricula related to specialized needs of people with dual diagnoses and delivery of training statewide.

Outcome:

OMRDD will assure that for those individuals with challenging behaviors requiring intervention, clear standards are identified in regulation that underscore the importance of a comprehensive approach to behavior support and management, and focus on prevention and early intervention.

Performance Measure:

- Development and promulgation of behavior management regulations.
- Decrease in the number of substantiated incidents of improper physical interventions.

Outcome:

Individuals with developmental disabilities, family members, and members of the public will be provided with increased, easily accessible information and stories of success about OMRDD mission, services, supports, and resources.

Performance Measure:

- Development of additional media products, including success stories, demonstrating innovative implementation of services that reflect the OMRDD transformational agenda.
- Increase in the number of OMRDD website hits.

Outcome:

IBR will work to reduce occurrence of developmental disabilities and improve the quality of life of affected individuals and their families in the State through an integrative approach that combines new advances in genetics, neuroscience, the behavioral sciences, and clinical science.

Performance Measures:

- Provision of multidisciplinary research platforms that support OMRDD's efforts to understand the causes, diagnoses, and treatment of autism and ASDs.
- Expansion of efforts in research areas for which IBR has been widely recognized as a center of excellence, including Fragile X syndrome, Down syndrome, Batten disease (neuronal ceroid lipofuscinoses, NCLs), and high-risk development.
- Expansion of a multidisciplinary research program on aging in individuals with mental retardation to better understand the neurobiological changes and the characteristics and special needs of this population.
- Employment of cutting-edge discoveries that are relevant to the developmental disabilities field, and translation of breakthroughs in neuroscience and genetics studies into new and refined methods for diagnosis, treatment, and prevention.
- Increase in provision of support for individuals who receive services from OMRDD, staff, families, and advocates, as well as professionals and lay people in the community.

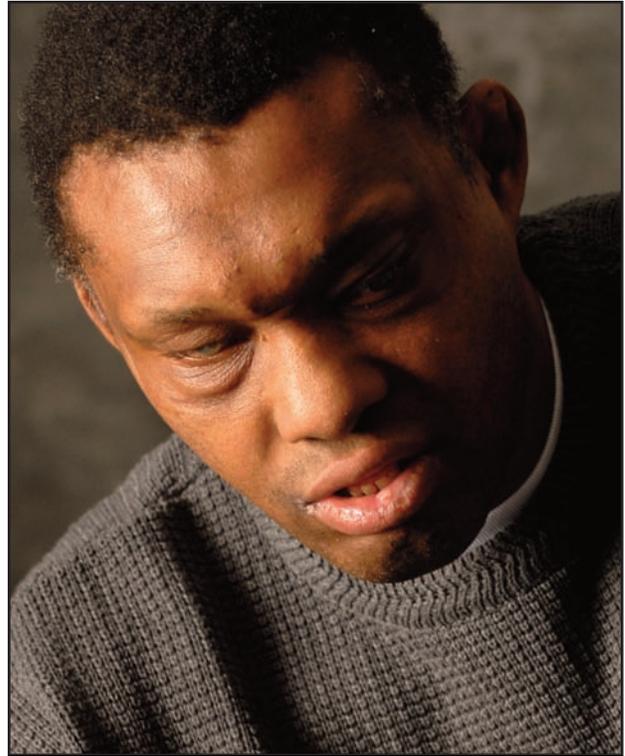
Chapter 10: Closing

As this present Five Year Plan demonstrates, New York citizens support a well developed, comprehensive, and varied array of supports and services for people with developmental disabilities and their families. With combined federal and State expenditures for developmental services exceeding \$6 billion dollars this year, the system has grown enormously over the past three decades in both resources and responsibilities.

At the most fundamental level, it is OMRDD's obligation to administer those resources prudently, equitably, and in a way that has the greatest positive impact on the lives of people with developmental disabilities and their communities. This shift, from looking primarily at the quantity of services provided, to now focusing on the changes in quality of life that those services produce, is extremely important. Overall customer satisfaction (which is a composite of a person's happiness with their relationships, home, daily routines, health, and resources) is the ultimate outcome OMRDD is most interested in assessing. Consequently, the evaluation of OMRDD and voluntary provider performance against well defined subjective and objective benchmarks must be done periodically in order to insure that the system is delivering the supports people need to lead richer lives. In sum, the system must become more outcome-oriented and performance-based.

As noted several times in the Plan, most system constituencies feel that under the visionary leadership of a new Governor and Commissioner, OMRDD is on the doorstep of great advances in the quality of service design and delivery, notwithstanding the momentary financial constraints the State is experiencing. In some ways, the budgeting challenge presented by the current economy presents a unique opportunity to do things differently - certainly more efficiently - even as the agency strives to increase quality. In some areas of operation, less may actually be more, if bureaucratic procedures can be streamlined and rigid service models rethought so that innovation can flourish.

OMRDD and its community of constituent groups – people with developmental disabilities, families, professionals, providers, local governments, and community organizations – have a proud history of achieving consensus, working together, and building what is truly a rich and diverse network of supports and services that could barely have been conceived of 30 years ago. The future is both exciting and daunting. But if the past is prelude, working together in common purpose, it is fascinating to wonder where we will be 30 years from now, and how much more advanced our service system and society might be in celebrating the differences that make us strong.





Appendix A

Summary from Public Forums and Public Hearing

Public Forums

During the month of June 2008 seven public forums were held throughout the State of New York to discuss the Five-Year Comprehensive Plan for the period 2008-2012. These forums were held to give self-advocates, family members, providers, advocates, and anyone else who was interested a chance to speak upon five main topics. These included:

1. OMRDD Vision Statement

People with developmental disabilities

- Enjoy meaningful relationships with friends, family, and others in their lives,
 - Experience personal health and growth,
 - Live in the home of their choice,
 - Fully participate in their communities.
- What issues most impact on OMRDD's ability to deliver the Vision Statement outcomes for the people we serve?
 - How can OMRDD and its partners (self-advocates, families, providers, and other agencies) improve services to deliver these outcomes for the people we serve?

2. Quality of Services and Customer Satisfaction

- How can we better involve self-advocates and families as productive partners?
- What are the key indicators of quality of the people we serve?
- What are the national and local best and promising practices NYS should consider implementing or replicating?

3. Building Community

- How can we promote full community participation and contribution?
- How can we encourage communities to become more responsive and inclusive?

4. Equity and Access to Services

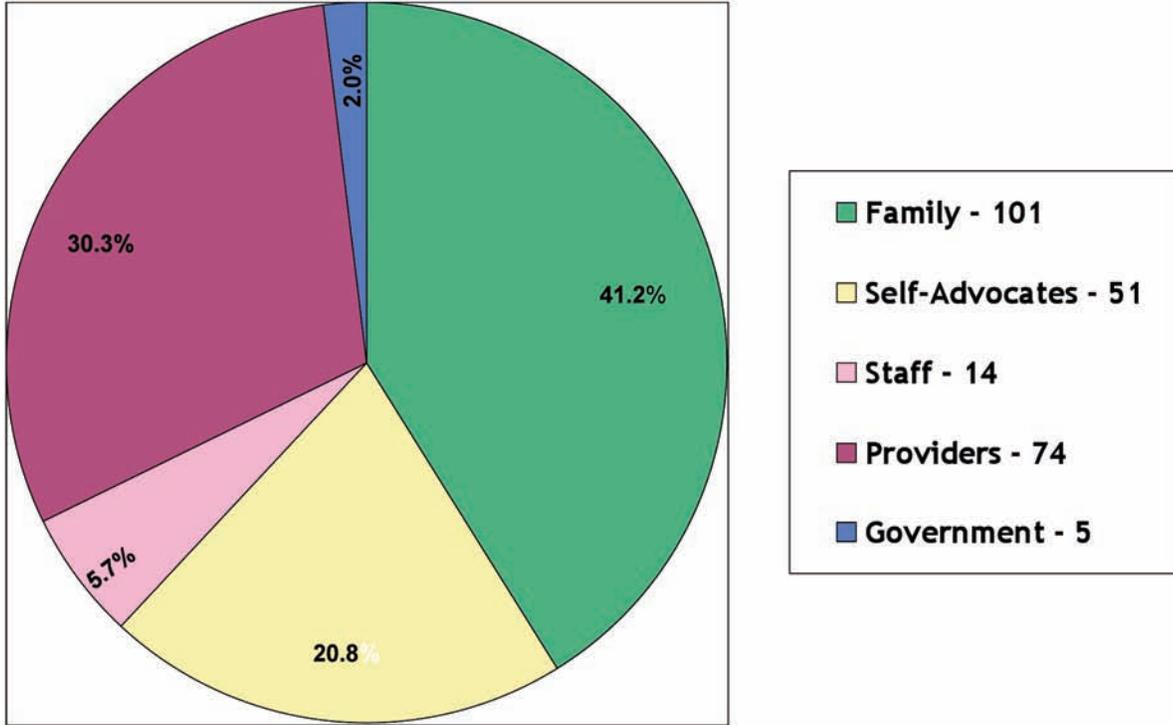
- How can OMRDD as a system better support people to truly make informed choices about their supports and services?
- How do we ensure that all individuals, including those with Autism Spectrum Disorders, the aging, people with medical frailties, children, and others, are provided fair and equitable access to person centered services?
- How do we better facilitate access to supports and services across service systems for people with multiple disability needs?

5. Workforce Capacity into the Future

- How do we sustain quality and stability in both direct support and clinical workforce areas in an era of changing workforce demographics?
- How do we develop the next generation of leaders throughout the system to meet the challenges of tomorrow?

Figure 1

All People who Presented or Submitted Testimony



As represented by the chart in Figure 1, approximately 240 people spoke at the forums, and over 90% of those speakers were family members, service providers, and self-advocates. As a result of the feedback OMRDD received from these speakers, a draft comprehensive plan was developed.

Figure 2

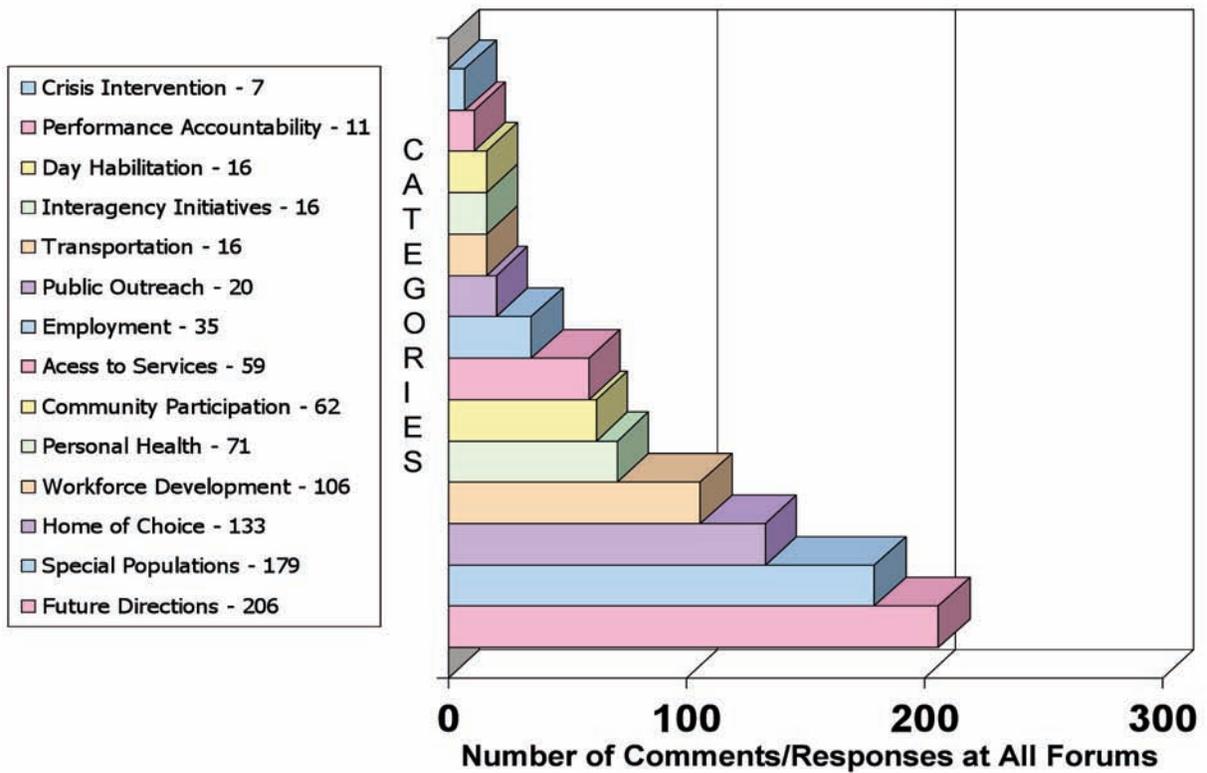
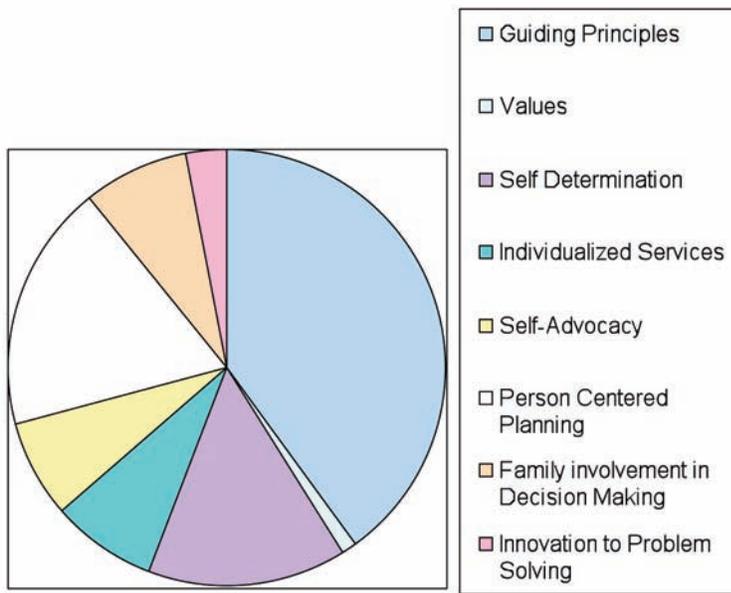
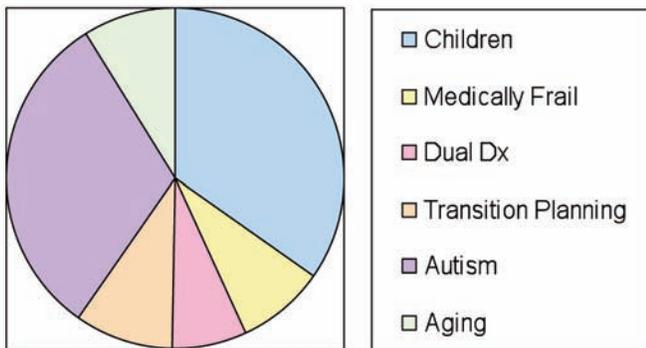


Figure 2 depicts **the main** categories that people chose to speak about at the forums by prevalence. From the forums, 62 topics were established that were broken up into 14 main categories with 48 subcategories. Among the most discussed main categories were future directions, special populations, home of choice, workforce development, and personal health. These categories are each composed of multiple subcategories. In turn, these categories and subcategories have been utilized to establish a major portion of the drafted 2008-2012 Comprehensive Plan.



Future Directions (Figure 3)

The most frequently discussed topics at the public forums related to future directions of OMRDD services. In particular, Guiding Principles such as “putting people first”, establishing equity of access, increasing partnership, and collaboration between service providers, families, and individuals with developmental disabilities were key issues. More opportunities for self-determination and person centered planning were also discussed frequently.

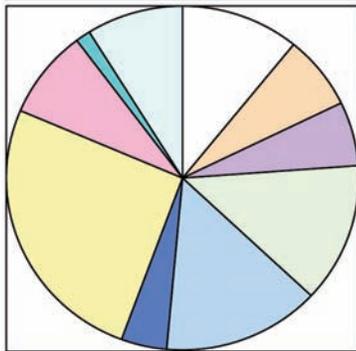


Special Populations (Figure 4)

Another widely-discussed topic encompassed the many Special Populations supported under the umbrella of OMRDD, including: children with disabilities, Autism/Autism Spectrum Disorders, dual diagnoses, and the medically frail. This group also comprises the sub-category of aging. Additionally, many parents discussed needs around transition planning for youth.



- Home of Your Own
- Nursing Homes/Assisted Living
- Family Care
- NYS CARES
- Shared Living
- Out-of-state Placement
- Family Support/FSS
- Waitlists
- Developmental Center Placements
- Individual Support Services

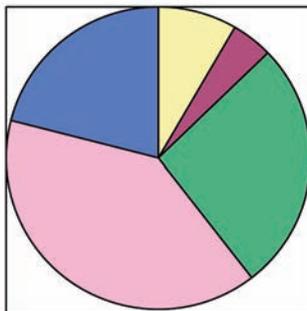


Home of Choice (Figure 5)

Living in the home of one’s personal choice was talked about most often in regards to family support and shared living. There is a necessity for families to find homes for their loved ones, and there is a necessity for people who want to live in shared living environments, whether = supervised, supportive, with friends or on their own, to be able to find those homes in a reasonable period of time. Home of Your Own (HOYO) and NYS-CARES were popular topics, as were family care and the services needed by families to support their loved ones at home.

Workforce Development

The category of Workforce Development was fourth in prevalence when considering main categories, but it was by far the single most discussed subcategory out of the 62 total topics. 11% of all comments made at the public forms pertained to workforce development, and almost 100% of those comments discussed the issue of recruitment and retention, as well as direct care staff salaries. Quality and training of the workforce were also stressed. Workforce development as a subcategory was mentioned almost twice as many times as the second most discussed subcategory – that of children.



- Nutrition
- Clinical
- Physical
- Behavioral
- Medicaid/Care

Personal Health (Figure 6)

Personal health was another issue that people talked about at the forums. Behavioral health, which includes timely access to psychiatric services, psychological crisis care, and crisis prevention, was the most frequently discussed. Physical health, including commentary on Prader-Willi Syndrome as well as medication certification and administration issues, also came up during the forums.

These brief paragraphs are only an overview of what was mentioned during the June forums. The following narrative further breaks down the specific comments and suggestions presented by the speakers regarding these categories reported above, as well as the other main and subcategories.

Future Directions:

Innovation in Finding Solutions in a Challenging Environment. Two people suggested circles of support to assist with job development and integration. One person said OMRDD should be more responsive to the changing needs of the people they serve. One advised that OMR compare NYS services with those of other states and provide that information to families and individuals.

Guiding Principles. A resounding request was stated for increased choice of services. Some thanked OMRDD for supporting the concept of “Nothing about us without us”. Some complimented and approved of OMRDD’s mission statement, while others offered suggestions for improvement. Some positive comments included appreciation for the concept of transparency, reflection on the “awesome” vision and values, and some lauded the positive changes over the years. A few suggested incorporating all developmental disabilities equally, promoting more self-determination, and ensuring partnerships with families. One said that the mission was great, but that it needed to be backed with additional funding. A person said that the OMRDD services and support need to mirror the vision and mission statement in order to ensure quality of life in residential and day services.

Another recurrent theme in testimonies was the recommendation that OMRDD collaborate with other agencies, most commonly mentioned being the Office of Mental Health (OMH), but also the Office of Alcohol and Substance Abuse Services (OASAS). Many talked about collaboration with developers to create more housing opportunities.

Values. A few commented that they do not like the “MR” part of OMRDD, and others agreed that they would like to see the community educated to eliminate derogatory labeling/name calling of individuals with developmental disabilities.

Family Involvement in Decision-making. Speakers encouraged the involvement of family and caregivers in the planning and development of new services. Some suggested involving parents in the policy making process. Parents spoke of advocating for their children. One person said the provider agencies need to understand what people really want, and not perpetuate old concepts in services that don’t really support what the people want.

Self-Advocacy. Speakers spoke positively of the Self-Advocacy Association, but some encouraged the group to ensure they speak for all people with developmental disabilities. Many expressed the need for more self-advocates. Some suggestions included self-advocates working with legislators and increased training in how to be advocates. One person suggested self-advocacy training for families. Stronger self-advocates can result in greater quality of services and can enhance staff abilities to be more effective. Several self-advocates expressed concerns related to availability and affordability of transportation.

Person Centered Planning. Many comments were provided on the benefits of person centered approaches to developing services. However, limitations in delivering person centered services exist. In particular, the amount of paperwork, regulatory oversight, amount of time waiting for service approvals, and the need to improve communications with parents were mentioned as areas needing improvement.

Individualized Services. A few expressed a wish that OMRDD be more flexible in terms of budgeting processes for individualized services. Others expressed a desire to have greater availability of choice in terms of service options, particularly in regards to day activities.

Self-Determination. A common wish was that the people with developmental disabilities be able to choose who they live with. Several complimented the Consolidated Supports and Services (CSS) initiative for self-determination, but they also expressed a wish for streamlining the process and stated that the program is too bureaucratic. One person said that CSS is one of the most progressive OMRDD programs, and others said it was wonderful. One said that CSS needs to “become more fluid.” A few commented that OMRDD should inform schools about CSS.

The OMRDD Vision:

People Live in the Home of their Choice.

NYS-CARES and Residential Needs. Some offered compliments to NYS-CARES, noting the increased residential options and continued allocation of resources. Others expressed an “overriding need” for NYS-CARES, were concerned about waitlists and the need for more residential opportunities, and recent reductions in funding allocations. People were concerned that the current rate of residential development could not keep up with the number of people on the waitlist. Many said they want OMRDD to provide for more choice about where and with whom they live. Three testifying expressed a need for more housing for individuals with Down’s syndrome. In general, favorable comments were heard with regards to group homes. Many stated the size of group homes should be limited to 6, and most prefer to keep the numbers even lower. Speakers stated fear about possible loss of availability of group homes for their children due to budget limitations. Some expressed that a group home may be more appropriate for some individuals than living alone. Some had residence-specific concerns, such as the need for residences that are “deaf-friendly”, one-story homes for those who cannot navigate stairs, and opportunities for people to have their own bedroom. Some talked about the potential for significant growth of the waitlist due to the growing numbers of people diagnosed with Autism Spectrum Disorders. One person mentioned that too many inappropriate hospitalizations occur due to lack of housing.

Self-Determination. Many applauded self-determination and the CSS initiative as a blessing, and said it was a program that could have a profound and “astronomical” impact on services delivery. One person said they love the self-directed program and expressed gratitude for OMRDD’s support. However, many also said the application process must be streamlined as it has become too bureaucratic, it takes too long and the budgeting process is too complicated. One person said many needs aren’t funded by CSS and Medicaid, and asked how these specialized requests should be paid for. Several were in favor of self-determination expansion.

Housing Initiatives. Some voiced resounding support for the Home of Your Own initiative, but added they would like it to be expanded. A few talked about choosing small houses or apartments that would better allow for people to develop neighborhood relationships. One person pointed out the challenges of home ownership when it comes to home improvements.

Family Care. A provider said “it is good to see the OMRDD Commissioner enhancing the family care program.” Another person stated that family care might be great option for some, but that it was not a viable choice for most individuals with Autism Spectrum Disorders. A few expressed the need for increased respite support for family care providers. Another suggested health insurance for family care providers.

Developmental Center Capacity. A few people expressed support for the movement of people from the Developmental Centers and stated their belief that group homes would provide for more appropriate living situations.

Marital Status. One person talked about the challenges in obtaining benefits and services when married.

Out-of-State Placements. Family members reflected they should not have to send their children out of State for services and that NYS should have adequate housing, respite, and behavioral management supports. A few said that income supports for families would help prevent out-of-State placements.

Family Support. Several talked about education and training for parents so they could better support their children. Navigating the special education system in schools was a concern to many. A few raised concerns about the “Medicaid-ing” of Family Support Services (FSS), and reflected on the potential local impacts. A few said that they would like their Developmental Disabilities Services Office to be more responsive to family support concerns.

Speakers strongly voiced the necessity for additional respite services. Respite was identified as a need for all populations, including the medically frail, children, people with autism, and family care providers. People stated that the availability of respite services could make the difference between placement and being able to support a child at home. Need for after school or after day-habilitation respite services were voiced. Also, some expressed a need for readily available crisis respite. Speakers noted the low pay respite providers receive.

People Fully Participate in their Communities.

Community Inclusion/Community Participation. Speakers frequently mentioned the need for and advantages of community inclusion and integration. The establishment of ongoing relationships with community members, family, direct support workers and others was a predominant desire among speakers. People with developmental disabilities stated a desire for meaningful activities, and fuller lives.

Many speakers said recreation is needed. Specifically, people requested more recreational programs promoting normalization and integration, programs for low-income people and people who live in rural settings. Many spoke of wanting a variety of recreational services to choose from, including art, music, dance, theatre, history, and sports. The provision of recreation was identified as a great way to facilitate inclusion. One speaker expressed a wish for wheelchair-accessible recreation. Some urged OMRDD to support more opportunities for volunteerism as a means of community involvement.

Employment. Many spoke of the need for more employment opportunities. People stated a desire for employment, but instead are in day programs. Some stated that people with disabilities get jobs that ignore their abilities, such as bagging, mopping, etc. One person said OMRDD should have as its highest priority the need to provide more meaningful options for work and productivity. Some speakers felt that pay is too low thereby limiting workers' ability to successfully participate in community events. A few suggested financial incentives for supported employment. The need for greater community involvement and acceptance was aptly stated by an individual who said, "We need to better explore work opportunities for those not able to be competitively employed, but able and social enough to participate in being a productive part of their community."

Day Habilitation. A few spoke in favor of day habilitation without walls. One person said day habilitation needs to be more individualized in order to facilitate greater involvement in the community. Several people expressed a need for extended adult day habilitation hours for family members who work. Many also talked about transportation problems, particularly distance from the home and lack of coordination to family schedules. It was suggested that after-day-habilitation services, coupled with transportation, be provided. It was also suggested that funding support for transportation be separated from Medicaid and day habilitation billing requirements.

Internship Program. Support for the recent internship initiative was heralded. An intern shared these thoughts: "Disabilities only become 'disabling' when they are not challenged. . . Not only am I doing everything I have always dreamed of doing helping people with disabilities to speak up for themselves, I am receiving outstanding support doing it. I am happier than I have ever been in my entire life with this job. It is my sincere hope that most everyone else working through this internship program feels the same way."

Faith Choices. A few speakers reminded OMR to consider the religious preferences of individuals, and build church/faith-based programs into inclusion activities as appropriate.

People Experience Personal Health and Growth.

Behavioral Health. Many speakers expressed a need for timely access to psychiatric services. Some recommended that Master's level behavior analysts be recognized as certified or licensed clinicians. The need for short-term psychological crisis care was identified. Speakers said crisis respite would help keep families intact. Some spoke about in-home crisis support and prevention services. One person said person centered planning was a key to developing services for behaviorally challenged individuals, and that OMRDD should develop a reimbursement methodology to enhance funding for agencies and direct care workers who provide support to individuals with these challenges.

Physical Health. The need for specialized Prader-Willi home services and support groups was expressed. Others expressed concern with dental hygiene and advised that care begin in childhood. Some parents said medication certification and administration restrictions prevent their children from traveling out-of-State or accessing more independent life styles. One advised OMRDD consider funding for alternative therapies. A parent talked about removal of human growth hormone from the controlled substance list. Some individuals expressed a need for better access to clinical services as the wait lists for doctor's appointments, especially specialty services such as psychiatry, can be too long. One speaker suggested that when people are admitted to group homes, they be screened for contagious diseases and that the home require proof of vaccinations.



Nutrition. Speakers advised OMR to involve dietitians rather than nurses in dietary planning. The importance of dietary choices to promote individualization was acknowledged, the need for exercise and heart-healthy practices was also promoted.

Benefits and Entitlements (Medicare, Medicaid). The gaps in Medicaid funded services were discussed by many. People expressed concern that not all supports desired through the self-determination initiative can be funded by Medicaid. Parents expressed confusion about what can and cannot be funded. Concern was voiced about the Medicaid buy-in. Some encouraged OMRDD to explore options other than Medicaid. Many expressed needs for FSS, and were concerned that Medicaid funds may be at risk.

Themes Affecting All Services

Workforce Development. By far, the highest level of comments was in regards to the retention and training of direct support workers. Many encouraged an increase in pay and/or monetary rewards and suggested professionalization through credentialing, establishment of national standards for direct support workers or development of college curricula such as the College of Direct Support. Others talked about providing training in core competencies and skills. Some spoke of the need to train staff and first responders of the police and legal systems. Several talked about an increased need for training in regards to autism. Some suggested mentor opportunities for students to encourage interest in the developmental disabilities field. Universally, a concern was voiced for improved recruitment methods. Particularly in the more costly housing markets, the lack of affordable workforce housing was identified as an issue. The turnover rate among direct support workers was acknowledged as an ongoing problem. Finally, a direct care staff member suggested that Executive staff engage in observations or practices that would facilitate a greater understanding of challenges in the workplace.

Public Information and Outreach. The need to better inform the public about services available through OMRDD was noted on numerous occasions. One speaker said, "OMRDD needs to get information to parents about services, information on behavior management and respite ... parents have no idea how to get their kid registered in OMRDD – they don't know where to start." Another stated that OMRDD is "the best kept secret." Several speakers said also said there is a need to educate the public about developmental disabilities, as there is still far too much discrimination. People stated their belief that broader dissemination of information would result in more acceptance within communities. Some speakers advised OMRDD to reach out to school-age children, both to inform and to tap into a new generation of potential direct support workers. One person suggested that OMR launch a statewide media campaign promoting employment as a direct service professional and valued career choice. Another suggested grass-roots meetings with local groups, public education and community building, as well as broad marketing activities. It was also suggested that training be provided for parents in regards to regulations and service options.

Crisis Intervention. Many spoke of the need for crisis respite services, including weekend services and crises residences to allow for speedier emergency room discharges. Some said there is a need for more home-based interventions and therapies, as well as timely psychiatry services.

Special Populations

Children. Several speakers discussed the need to inform schools about CSS, and one person suggested that OMRDD partner with schools at earlier life stages. Transportation problems to and from schools due to distance and lengthy commutes were mentioned by many speakers. It was suggested that VESID and schools enhance their partnership to better prepare youth for post education years. Some said the special education system is difficult to navigate. Several spoke of the need for after school programs. Parents noted their desire have kids involved in the community. One speaker said OMRDD should strengthen communications with parent advocacy groups.

Some suggested that OMRDD should establish and fund programs in each county to ensure parent access to highly-trained special education advocates. One person recommended that OMRDD fund a team to advocate for children across the home, community and school in order to help prevent segregation in schools and receive consistent behavioral support at home.

Some suggested training centers be linked with teen centers so that kids could learn while at school and then

after school services would be available to provide for socialization opportunities. Teen needs were referenced, with a particular concern about gaps in services as after school programs are no longer available for typical youth. Some voiced a concern about a need for a middle ground in regards to regents versus GED diplomas. Some asked why Applied Behavior Analysis services are eliminated as children age to adulthood when they still have the same needs associated with autism. Statistical rates on unintentional injury of children with disabilities were identified to be far above that of the general population. Some felt that public schools place too much focus on academics and not enough on life skills.

Transition Planning. One person said there is insufficient support for job placements during transitions and that transition planning was essential to successful adult living. A suggestion was made to have district planning coordinators for post-graduation services, and that OMRDD should send an individual to every transition meeting.

Quite a few families talked about the need for transition services for children with autism, both at the middle school age and upon finishing high school. Some spoke of the need to integrate those with autism spectrum disorders in schools.

One person suggested collecting data about how youth determine career paths, are transitioning to adult work, and the availability of “real” jobs that provide living wages.

Autism. Autism was a frequently mentioned topic among speakers. Many spoke in support of Applied Behavior Analysis (ABA) programs and positions. Needs were diverse. Some spoke in favor of the OMRDD Autism Platform, saying it is exciting and innovative, but needs more. Others praised the Autism Research Consortium managed by the IBR. One speaker suggested that parents be included on the Interagency Task Force on autism. Many parents emphasized the uniqueness of individuals with autism and encouraged increased staff training, as well as customized services. Many spoke about the need for support services for parents of individuals with autism. Many voiced concern that people with autism are often perceived as having behavioral issues. Some parents spoke of the need for early intervention. One person expressed concern that the increasing number of people diagnosed with autism may cause the NYS-CARES registration list to swell. A speaker suggested OMRDD establish “a task force that can harness the energy, wisdom, skill and enthusiasm of...groups like Autism Speaks and Simon’s Foundation...to ascertain the most effective solutions to the most urgent needs of the Autistic community.” Several parents talked about the necessity for increased training of school personnel in regards to autism. One person suggested that OMRDD and the Criminal Justice system collaborate to enhance protections for people with autism. Quite a few people spoke about the need for more vocational training and community integration opportunities. One speaker stated that NYS needs an autism task force to develop an autism provider training program, training for direct care and administrative staff, removal of financial disincentives, and the establishment of an adult Autism Medicaid Waiver.

Aging. Many spoke of the need for assistance to families who are either aging themselves or have an aging family member with a developmental disability in their home. Alzheimer’s and dementia were mentioned as contributing to challenges in keeping a family together. People stated that more services are needed to help prevent unnecessary nursing home placements. Some spoke about a need for Alzheimer’s based homes and the need for dementia-capable day programs. One person said that people are waiting up to six months for repairs of durable medical equipment. A few said that OMRDD needs to offer more choice to people with medical care needs as nursing homes are not seen as desirable options. A few mentioned that self-advocacy in nursing home settings is not always supported. Some were concerned about the isolation, both medical and social, in nursing homes.

People who have Medical Frailties. Many speakers referred to a need for more respite services and homes for the medically frail. Some spoke about medically involved children and the need for additional funding. One person proposed 1:1 nursing care and therapy for the medically frail individuals. A speaker felt that the medically frail population is under served and that there is a lack of in-patient acute psychiatric care for people with complex needs.

Dual Diagnoses. Many said they would like to see increased collaboration between OMH and OMRDD for blended services for the dually diagnosed. Others said more funding is required for dual diagnosis services. One person noted that people with predatory behaviors cannot live in communities without adequate supports. A speaker advocated for the development of a dispute resolution process for OMH/OMRDD for the dually diagnosed.

Fetal Alcohol Syndrome Disorders. One parent spoke about a lack of appropriate services for individuals with Fetal Alcohol Syndrome Disorders (FASD) in the adult system, and the need for training for professionals regarding diagnosis and treatment. The parent advised that OMRDD should create policy and regulations regarding FASD, as Fetal Alcohol Syndrome (FAS) is the leading cause of developmental disabilities in the world, and OMRDD eligibility for services is sometimes difficult to establish.

Access to and Coordination of Services. Many spoke of the difficulties inherent in the eligibility process, which one parent referred to as “cumbersome and capricious.” Several referred to a lack of coordination between OMH and OMRDD when determining eligibility for services. A suggestion was provided to have a centralized compendium of cases of people with multiple diagnoses with brief, periodic status reports to facilitate efficiency of dispositions. Some said there is a need for adequate funding for dual diagnosis services. A parent said that a lot of people get services as a child, but then face barriers as adults. One parent said it is difficult to access appropriate assistive technologies. A service provider indicated a need for more workshops in order to expand self-determination options. One speaker suggested a central registry for roommate matching services.

A parent said Medicaid Service Coordinators (MSCs) don’t attend IEP meetings because of high caseloads. Some people talked about turnover rates and the difficulty in replacing MSCs. A few commented that MSCs do well with paperwork, but have difficulty interacting with families. Speakers advised additional training for MSCs and appropriate supervision when they are working with parents.

Home and Community Based Services. A recurrent theme among testifiers was the need for consistent residential habilitation and respite services. A few commented that at home residential habilitation is difficult to implement due to lack of staff, and new methodologies must allow for quality training, supervision and wages. Some people spoke about seeking approvals for more homes for both long-term care and respite. A person said too much money is being spent on unnecessary 24-hour care.

Transportation. Transportation was an issue of concern to many speakers. People stated the lack of available public transportation, particularly after specific hours, presents many challenges. One parent said, “To be an active person in your community you need to get around: jobs, shopping, doctor appointments, friends, activities, church, etc. How do we fund transportation needs? There are few buses, taxis are expensive; gas is expensive.” Self-advocates voiced similar concerns, saying it is difficult to get out without access to transportation that is affordable, particularly if they live in their own apartments. Some urged OMRDD to consider other options for access to meetings, such as video conference capabilities. Transportation, in relation to working parents of youth and adults living at home, was often mentioned as a concern, particularly in rural areas where resources may be a long distance away. One parent said, “Parents have to work. Either adult day habilitation hours need to be extended to reflect the real world hours of work, or there need to be more after-day-habilitation programs in rural, urban, and suburban areas, all with provided transportation.” One speaker said the Most Integrated Setting Coordinating Council (MISCC) is an awesome and inclusive process for addressing housing needs universal to all people with disabilities, but that transportation has been an challenge.

Local Services Planning. One speaker discussed cross-systems sharing of local resources. A couple of speakers commented positively on the recent efforts between the State agencies to facilitate coordinated local planning for services.

Performance Accountability and Quality Management. One person said OMRDD needs to focus more on quality of life indicators by talking to the service recipients, not by just checking paperwork. Another said OMRDD should encourage DDSO partnership with parents and individuals to enhance quality and satisfaction. A few spoke about the need to maintain adequate supervision of direct care providers to make sure agencies and staff are doing what they’re supposed to be doing.

It was suggested that OMRDD support statewide legislation to establish a registry of all human services workers who are subject to the Criminal Background Check law and were terminated because of abuse, neglect, or misconduct.

National Core Indicators. A few speakers talked about the National Core Indicators (NCI) project. The NCI survey activities will help with measuring systems wide outcomes and will generate metrics that provide comparisons of services. It was advocated that the surveys be completed in a place chosen by the person. One person suggested that self-advocates be paid to assist with interviews.

Streamlining how OMRDD does Business/Paperwork. Speakers appreciated the opportunity to attend a public



forum, and advised that OMRDD hold more. Several spoke about the timeliness of service provision, and some said that OMRDD should be more responsive to the changing needs of people. Many comments were received about the need to streamline paperwork.

Public Hearing

On September 8, 2008 OMRDD held a Public Hearing on the draft OMRDD Five Year Comprehensive Plan. This Hearing was held at three locations in the State and was conducted as a live video-conference with Commissioner Diana Jones Ritter. The purpose of the Hearing was to hear from self-advocates, parents of people with developmental disabilities as well as other family members, non-profit providers, professionals, advocates, and other interested parties about how well the draft plan addressed needs and issues into the future. OMRDD used the ideas, suggestions, and comments received through the Public Hearing to further refine the proposed Five Year Comprehensive Plan for Services.

43 individuals testified or provided written comments on the draft Plan. The breakdown of people who spoke or provided testimony is as follows: 17 self-advocates, 16 parents, 7 providers, 2 County Directors, and 1 workforce representative.

There were a significant number of favorable comments about the draft Five Year Comprehensive Plan. Across groups reporting, many people commented about the thoroughness of the Plan, and provided positive feedback about the future direction of the service system as laid out in the Plan. Of particular note were favorable comments about the focus on person centered supports, ability for people to have more choice and control in services, and the new focus on cross-systems collaboration.

Issues raised largely paralleled themes identified through the public forums conducted in June, 2008. Concerns were reiterated about access to services in the future, particularly for out-of-home supports. The Commissioner reiterated OMRDD's commitment to supporting people according to their needs and desires in very person-focused ways, and stated there would be continued development of both non-traditional supports and services as well as supervised group homes if that is what people need.

Also, as noted in the June forums, themes from the Public Hearing included major concerns about transportation, employment, autism, eligibility, workforce, and supports for families.

An excellent suggestion was provided by a parent that OMRDD make available a more user-friendly vehicle for communicating the system's key priorities. OMRDD will use various media to share information about the future directions of the service system on a statewide basis.

Appendix B

Summary from the National Core Indicators Project

Introduction

The following report summarizes results from OMRDD's first National Core Indicators (NCI) data collection effort, giving special attention to our "People First" goals: home, health, relationships, and jobs/activities. In addition to these core areas, OMRDD will also analyze indicators of satisfaction levels, choice and individualization. These results will be part of a baseline for future planning activities.

By participating in the NCI process on an annual basis, OMRDD will be able to track progress made in these "People First" areas and monitor trends in other areas as well. In addition, the Human Services Research Institute (HSRI), the organization managing the national database, will provide a report comparing the performance of New York and the other participating states. NCI is becoming an integral part of DD quality management systems around the country as over half the states in the nation now participate. OMRDD's larger goal is to better support people with developmental disabilities and their families. The NCI Consumer Survey is one part of an ongoing dialog between OMRDD and the people OMRDD serves. OMRDD seeks to determine what works and what needs to be modified as a course is charted for the future.

Another aim of this endeavor is to make the NCI data part of a metrics-based quality management system that captures the extent to which OMRDD's services enhance the quality of life of the people served, and to use the survey results to create an action plan for improving the quality of life for all people with developmental disabilities in NYS.

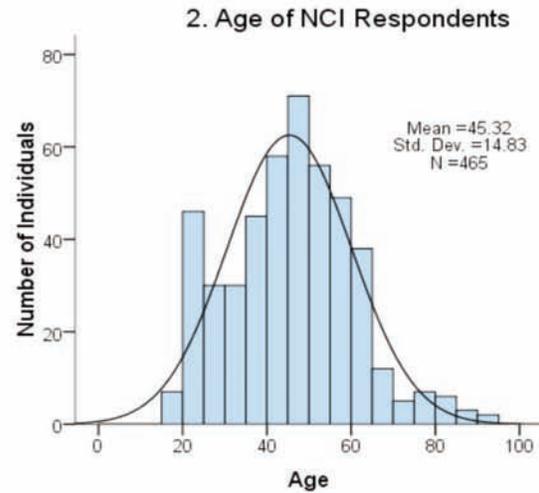
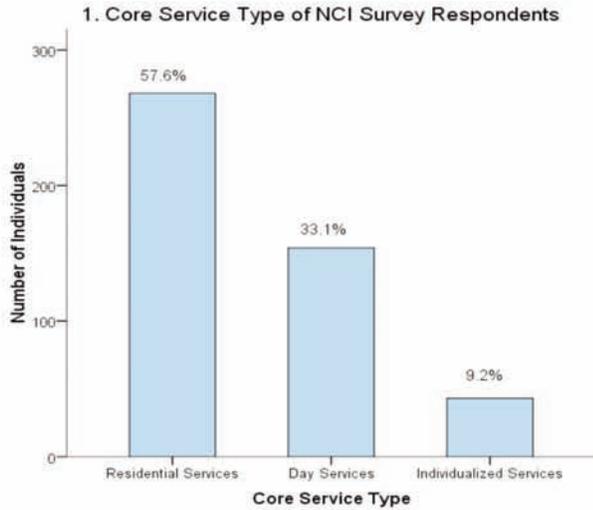
Methodology

Sample. Each NCI state must conduct a minimum of 400 interviews from a random sample of individuals over the age of 18 who receive at least one service besides case management. According to HSRI, a sample size of 400 allows statistically valid comparisons across states with a 95% confidence level. New York's sample was stratified by DDSO in order to accurately represent the people served in every region of the state. Further, the New York sample was also designed to proportionately represent three core types of services offered by OMRDD: residential, day, and individualized services. Individuals receiving residential services, regardless of other services received, were assigned to the residential services group. Those receiving day services, but not residential services, were assigned to the day group. Finally, those receiving individualized services (e.g., respite, recreation, counseling, at-home residential habilitation) and not receiving either residential or day services were placed in the individualized services group. This strategy ensured that our sample accurately reflected the population of individuals receiving OMRDD services. Our sample of 465 individuals thus represents a balanced, random selection of the key types of people served across NYS.

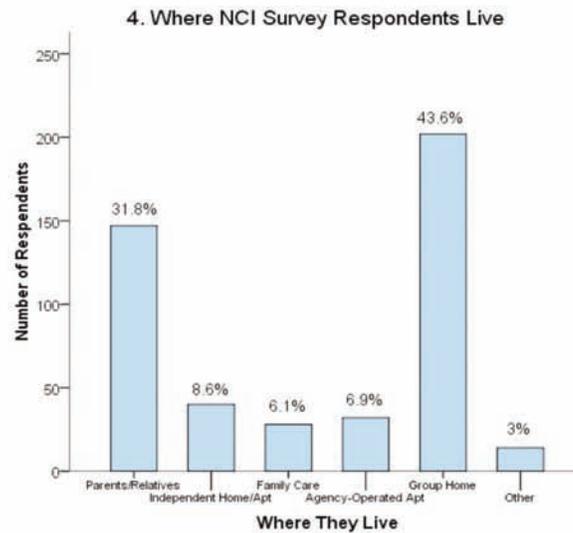
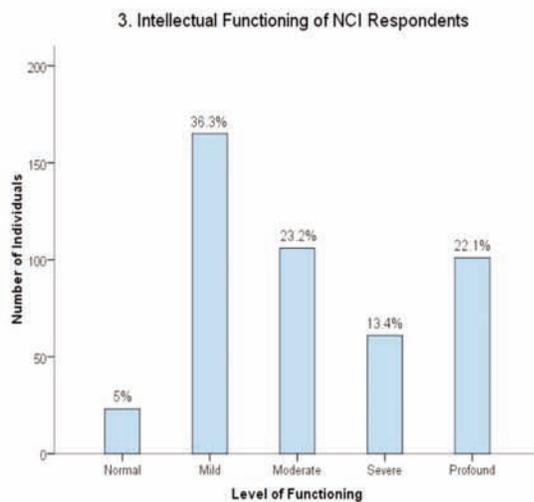
Data Collection. Interviewers and Developmental Disabilities Services Office (DDSO) staff participated in a video conference hosted by HSRI and OMRDD's Planning and Research Units that focused on training interviewers to conduct the NCI survey follow interview protocols. The purpose of the training was to teach interviewing skills, to standardize the way in which NCI survey questions were asked and to provide interviewers with the opportunity to raise questions they might have. The training was completed in February of 2008, and the process of data collection began immediately thereafter. To prepare for field interviews, research staff performed the sampling and, with the assistance of Information Management Services, prepared lists of selected respondents, including backups for those respondents who declined to participate or could not be contacted.

Prior to interviewing participants, Medicaid Service Coordinators (MSCs) completed the background portion of the NCI Consumer Survey. The MSCs were also able to correct and expand contact information, which was later used by Division of Quality Management and DDSO staff to arrange interviews during times and locations that were convenient for the individuals who agreed to participate. Interviewing was completed in a four month period from March to June of 2008.

Sample Characteristics. The four graphs that follow describe various characteristics of the 465 individuals who were interviewed in the NCI survey. The first graph shows the breakdown of respondents by their core service



The second graph shows that the age distribution of the 465 individuals participating in the NCI survey, keeping in mind that the survey only includes people 18 and over. The distribution is fairly symmetrical and normal-like, as indicated by the normal curve superimposed on the graph. With a mean age of about 45, the sample is somewhat older than the mean for all OMRDD participants of 40. Some of this difference is likely due to the slight overrepresentation of residential participants in the sample.



The third plot portrays the intellectual functioning levels among sample respondents. People with a wide range of intellectual capabilities participated in the survey, with help if necessary. About 40% of the respondents were people with normal or, at most, mild intellectual challenges. About 36% of the respondents were individuals with severe/profound challenges. The NCI protocol includes a section of the form where people who need accommodations can answer with assistance of caregivers. Finally, range matches very well with the distribution of intellectual capabilities in the larger group of people served by OMRDD.

The fourth graph describes the living situations of survey respondents, capturing a full range of residential possibilities. About 40% of the participants live with family (31.8%) or on their own (8.6%). The independent-living group, in which agencies may provide support, but the person owns or leases the home, is particularly interesting because it provides the first solid estimate of the size of this group. A little over half of the group lives in homes certified by OMRDD, though some (6.1%) of these individuals live in small home-like settings (Family Care) and some (6.9%) live in an apartment operated by an agency. All in all, living arrangements are quite

varied. We now turn to what these people told their interviewers.

Results. The following tables examine how OMRDD is faring in relation to its core values. For each of seven content areas (home, health, relationships, day / activities, choice and individualization), respondents were asked questions with responses like *yes/sometimes/no* or *never/once in a while/usually/always*. In the tables that follow, ‘Yes’ includes ‘Sometimes’ for questions with responses worded as such. And for responses of ‘Never’, ‘Once in a While’, ‘usually’ and ‘Always’, Percent ‘Yes’ includes ‘Usually’ and ‘Always.’ Keep in mind that these are not the only questions that were asked, but the ones reported below were judged to be central items. In the first table (below), questions related to the individual’s home are summarized.

As the first table shows, the vast majority of NCI survey respondents are very positive about almost all aspects of their home life, with positive responses approaching 100%. The least positive result has to do with whether or not the participant is afraid at home with nearly one in five respondents saying they are sometimes afraid at home, despite the almost universal positive sentiments about their homes. The large number of positive responses hints that of the four “People First” areas, home life may be the strongest.

1. Home	Percent ‘Yes’
Is your home staff nice and polite to you?	98.2%
Does the staff at your home work with you to meet your goals and needs?	95.5%
Do you usually get along with people you live with in your home?	94.6%
Do you like your home or where you live?	93.2%
Do people let you know before coming into your bedroom?	91.0%
Are you ever scared or afraid when you are at home?	18.3%

Note: Percent ‘Yes’ includes ‘Sometimes’ for questions with responses worded as such. For responses of ‘Never’, ‘Once in a While’, ‘Usually’ and ‘Always’, Percent ‘Yes’ includes ‘Usually’ and ‘Always’.

While the second table (below) shows that, in general, people enjoy their work and other daytime activities, there is more variability of opinion expressed here. There is almost universal approval of day staff, and respondents have a strong liking of their day activity. From there opinions are more critical. About 22% of the individuals interviewed expressed some level of dissatisfaction with the chance they had to earn good money and 16% had some level of dissatisfaction with number of hours they work. A sizable percentage of people (36%) said that they do not have the choice to stop going to day services even though they are old enough to retire. These results speak to some clear issues regarding work and may indicate that there is not adequate staffing at home to accommodate individuals who want to retire from their day activity.

2. Work / Daytime Activities.....	Percent ‘Yes’
Is day staff nice and polite to you?	98.9%
Do you like working or going to day activity?	95.4%
Do you work as many hours as you want?	84.0%
Do you have a chance to earn good money?	77.7%
If you are old enough to retire, can you stop working or stop going to day services?	63.6%

Note: Percent ‘Yes’ includes ‘Sometimes’ for questions with responses worded as such. For responses of ‘Never’, ‘Once in a While’, ‘Usually’ and ‘Always’, Percent ‘Yes’ is includes ‘Usually’ and ‘Always’.

The third table focuses on relationships. In general, most respondent reported that they have friends, or at least someone to talk to when something is bothering them. Although about 90% of the respondents indicated that they do have friends and 84% have a best friend, only about 74% reported that these friends initiate doing things with them. Additionally, about 39% of the respondents reported being sometimes or often lonely. The responses to these two items may hint that while individuals with disabilities do reach out to others, in some cases, others do not always reach out to them.

3. Relationships	Percent 'Yes'
Do you have someone to talk to when something is bothering you?	95.2%
Do people help you to learn new things?.....	90.0%
Do you have friends you like to talk to or do things with?	89.4%
Do you have a best friend or someone you are really close to?	84.3%
Do your friends ask you to do things with them?	74.1%
Are you (sometimes or often) lonely?	38.5%

Note: Percent 'Yes' includes 'Sometimes' for questions with responses worded as such. For responses of 'Never', 'Once in a While', 'Usually' and 'Always', Percent 'Yes' is includes 'Usually' and 'Always'.

Overall, most respondents agreed that they are in good health. Nonetheless, about one third of respondents reported that weight was a concern and about three in ten reported that they were not physically active. These two items suggest that nutrition and exercise are issues for individuals with developmental disabilities just as they are for the general American public. About 18% of respondents said that they do not always get mental health services when they are needed. This survey item should be closely monitored over time, given the growing number of individuals with both developmental and mental health issues OMRDD serves.

4. Health	Percent 'Yes'
Do you eat healthy foods on most days (fruits, vegetables, yogurt, etc.)?	98.3%
Do you get enough sleep?.....	93.9%
Is your health generally good?	85.1%
Do you get mental health services (psychology, psychiatry, counseling, etc.) when you need them?.....	82.4%
Are you physically active (somewhat or very).....	71.8%
Is weight a concern (either under- or over-weight)?.....	33.8%

Note: Percent 'Yes' includes 'Sometimes' for questions with responses worded as such. For responses of 'Never', 'Once in a While', 'Usually' and 'Always', Percent 'Yes' is includes 'Usually' and 'Always'.

The fifth table addresses the treatment of people as individuals. Generally, people express satisfaction with the process of planning their services. The two weakest items are focused on the large and small. Only about 80% report the ability to go out and spontaneously do small, everyday things; a similar percentage felt that they have the support to make a major life change.



5. Person centeredness /Individualized Services	Percent 'Yes'
Can you see friends when you want to see them?	95.3%
Do the staff at your home help you to advocate for yourself?	90.0%
Do your planning meetings about the services you get at home include the people you want there?	89.1%
When talking about the services you get at home, do people listen to you and do the things you asked for?	87.6%
If you want to run an errand or go out for entertainment, can you just decide and go?.....	80.5%
When you want to make a big change in your life (like moving into your own home/apartment or getting a new job), do staff at home support you?.....	79.7%

Note: Percent 'Yes' includes 'Sometimes' for questions with responses worded as such. For responses of 'Never', 'Once in a While', 'Usually' and 'Always', Percent 'Yes' is includes 'Usually' and 'Always'.

Of all the categories reported here, choice is the single area with the greatest room for improvement. Respondents report that they do have some degree of control over their free time. However, responses to the balance of the items hover around 50%. The availability is a 50/50 proposition for a range of items, from the big (choose home, choose job) or small (daily schedule).

6. Choice Questions	Percent 'Yes'
Do you choose what to do with your free time?	85.5%
Do you decide your daily schedule?	57.7%
Did you choose the place you work (or go during the day)?	51.4%
Do you choose or pick who helps you at home?	51.1%
Did you choose home or place where you live?	46.3%

Note: Percent 'Yes' includes 'Sometimes' for questions with responses worded as such. For responses of 'Never', 'Once in a While', 'Usually' and 'Always', Percent 'Yes' is includes 'Usually' and 'Always'.

The final table addresses bottom line issues: how satisfied are people with their services and their life. All the services are rated at better than 90%, from a high for their home (97%) to mental health services (91%). Life is another matter. Despite reporting high satisfaction with services, only about 83% of the respondents report that they are happy with their lives.

7. Satisfaction Questions	Percent Yes
In general, are you satisfied with services you get at home?	97.2%
Are you satisfied with the way your doctors treat you?	96.1%
Are you satisfied with your other health services (e.g., PT, OT)?.....	93.9%
Are you satisfied with your mental health services?.....	91.2%
Are you happy with your life?.....	82.8%

Note: Percent 'Yes' includes 'Sometimes' for questions with responses worded as such. For responses of 'Never', 'Once in a While', 'Usually' and 'Always', Percent 'Yes' is includes 'Usually' and 'Always'.

Appendix C

Summary from 2009 County Plans

The 2009 Local Services Plan Guidelines were revised to reflect an integrated local approach that is applicable to all three NYS Mental Hygiene Agencies: the Office of Alcoholism and Substance Abuse (OASAS), the Office of Mental Health (OMH), and the Office of Mental Retardation and Developmental Disabilities (OMRDD). For the first time, the three agencies collaborated within the context of a web-based system to provide consistent and efficient documentation of the needs of the individuals served by the human services systems. This approach builds on the Governor’s “People First” platform to assure comprehensive planning, development, and implementation of services and to avoid gaps in services for individuals with multiple disabilities.

The web-based application allows counties to identify priorities for all three disability populations as well as to identify those issues that cross the traditional lines of each agency’s service system. Through the more integrated planning process, the abilities of the counties to address cross-system issues that impact individuals with co-occurring disorders are enhanced.

All counties and the City of New York submitted a plan that identifies priority outcomes and focus areas. These Plans are available for review on the web-based system. When Priority Outcomes were analyzed using filters that included OMRDD, OMH, and OASAS and all possible disability groups, 708 Priority Outcomes were identified; additional filters were used to analyze Priority Outcomes based on collaboration between combinations of the agencies and on the number of Priority Outcomes that targeted individuals with developmental disabilities. The breakdown and comparison of this analysis is reflected in Table A, below.

AGENCY COLLABORATION	PRIORITY OUTCOMES TARGETING ALL DISABILITIES	PRIORITY OUTCOMES TARGETING ONLY MR/DD DISABILITY
OMRDD/OMH/OASAS	708	152
OASAS/OMRDD	0	0
OASAS/OMH	66	4
OMH/OMRDD	42	40
OMRDD ONLY	208	208

Each county is responsible to work with the State to develop the local services program and to plan for its citizens with developmental disabilities. In order to accomplish this, the county must research, review and determine local best practices, issues, concerns and needs in terms of supports, services and infrastructure. Each county is required to submit an annual plan to OMRDD, which will be integrated with the planning processes of OMH and OASAS. To accomplish this integrated approach, local counties must undertake a discovery process based on working relationships between the Developmental Disabilities Services Offices (DDSOs), counties or boroughs, individuals with developmental disabilities, their families or advocates, voluntary providers and other State agencies. Local issues and needs are identified through the discovery process, and the development of strategies results from an ongoing multi-faceted needs assessment process through which Priority Outcomes are identified.



Priority Outcomes and Focus Areas

A Priority Outcome is a broad statement of a realistic and desirable goal the county hopes to achieve over a period of time. The statement reflects the mission, vision, and values of the local system of care and is constructed in a way that permits the articulation of a multi-year plan of action toward achieving the outcome.

Each Priority Outcome addresses specific individual and/or system focus areas. An individual focus pertains to quality of life and those components of well-being that are essential to an individual’s overall growth, satisfaction, and happiness. A system focus results in a desirable, measurable outcome for the service system.

Most Priority Outcomes cite a number of focus areas, one of which is specifically targeted by the activities defined in the Priority Outcome. The additional focus areas identified are pertinent in developing strategies necessary to accomplish other Priority Outcomes but are not the targeted goal defined in that Priority Outcome. For example, there were 30 Priority Outcomes that identified Transportation/Community Supports as a focus area necessary to support the MR/DD population in the respective counties. Of these 30, however, only 11 Priority Outcomes specifically targeted the development of additional transportation resources or the enhancement of existing transportation resources. The other 19 Priority Outcomes identified Transportation/Community Supports as necessary strategies to accomplish another outcome, such as Increase in Employment, Increased Access and Stability in Housing, Increased Social Connectedness, and so on.

Table B identifies the frequency with which each Focus Area is identified as part of a Priority Outcome. Focus Areas are listed in the first column. The second column indicates how frequently each focus area is identified in Priority Outcomes defined through the collaboration of OMRDD/OMH/OASAS. These data were obtained through the web-based system using OMRDD/OMH/OASAS and each Focus Area as the filters. The third column identifies the number of Priority Outcomes that target individuals in the MR/DD population and are designed to accomplish a specific goal related to the particular Focus Area. In order to collect the data listed in the third column, Priority Outcomes were identified from the web-based system using “OMRDD only” and “MR/DD disability only” as filters. An analysis of the narrative content of each Priority Outcome identified through these filters determined if the Focus Area was the targeted goal of the Outcome or part of a strategy. Only those Priority Outcomes specifically targeting the Focus Area are included in the numbers recorded in the third column.

TABLE B: TARGETED FOCUS AREAS

FOCUS AREA	OMRDD/OMH/OASAS	# OF OMRDD TARGETED PRIORITIES AFTER ANALYSIS OF NARRATIVES
HOUSING	49	25
EMPLOYMENT	43	12
HEALTH	60	8
SOCIAL CONNECTEDNESS	82	18
SELF-DIRECTION	54	10
TRANSPORTATION	42	9
AVAILABILITY OF SERVICES	102	56
ABSTINENCE FROM SUBSTANCES	51	0
DECREASED CRIMINAL JUSTICE INVOLVEMENT	46	0
INCREASED RETENTION IN TREATMENT	57	1
COST EFFECTIVENESS	58	0
EVIDENCE-BASED PRACTICES	58	2
QUALITY MANAGEMENT	43	2
CROSS-SYSTEM COLLABORATION	96	20
WORKFORCE DEVELOPMENT	39	15



The information in Table B was then reviewed to determine which Focus Areas were identified most frequently by the Counties as areas of need. The information in Table C, below, reflects this information. The data was collected using the information in the third column of Table B, which identifies the Focus Areas targeted based on an analysis of each Priority Outcome narrative.

Percentages were determined using the total number of Priority Outcomes identified using “OMRDD Only” and “MR/DD disability only” as the filters (208).

TABLE C: MOST FREQUENTLY IDENTIFIED FOCUS AREAS

FOCUS AREA	FREQUENCY OF IDENTIFICATION
INCREASED AVAILABILITY OF SERVICES26%
HOUSING12%
CROSS SYSTEM COLLABORATION10%
SOCIAL CONNECTEDNESS8%
WORKFORCE DEVELOPMENT7%
EMPLOYMENT6%
SELF DIRECTION4%
TRANSPORTATION4%
HEALTH AND WELLNESS3%

Focus Areas not listed in Table C were identified less than 1% of the time.

Of the 208 Priority Outcomes identified by OMRDD, 107 listed Increased Availability of Services as a focus area (51%). After reviewing each narrative, 56 of these (26%) were noted as specifically pinpointing actions and initiatives designed to increase services. Improving and streamlining access to information, outreach, and training were identified most frequently (25%) in these narratives. Counties have initiated actions to assure dissemination of more detailed and more accurate information through local agencies, particularly the local school districts. Specific plans for improving supports and communication during Transition were identified, as well as developing greater access to respite services and other in-home supports for families. Individual counties also presented goals to increase services to individuals with Autism (3%).

The second most frequently identified need was Increased Access and Stability in Housing. Counties identified Housing in 63 Priority Outcomes (30%), and of these 63, 25 (12%) Priority Outcomes identified tangible plans for developing housing opportunities in the respective county. Housing initiatives included opening new IRAs, modifying and renovating existing IRAs to address specific needs of individuals, and pursuing opportunities for apartments and supportive apartments.

The third most frequently identified need was Cross-System Collaboration/Service Integration. This was identified in 96 Priority Outcomes (14%) using all three agencies – “OMRDD/OMH/OASAS” – as the filter. When “OMRDD Only” was used as the filter, Cross-System Collaboration/Service Integration was identified in 34 Priority Outcomes (16%) and was the targeted goal of 20 Priority Outcomes (10%). It is significant that of these 20, ten (50%) identify collaborative efforts with school districts and VESID as the primary focus, citing the importance of facilitating effective transition from educational to adult services. This corroborates the need for more outreach and dissemination of information which was frequently cited in the Priority Outcomes that targeted Increased Availability of Services as a primary goal.

OMRDD Vision and Mission

The Guidelines for developmental disabilities planning were designed to support the OMRDD Vision Statement: People with developmental disabilities enjoy meaningful relationships with friends, family, and others in their lives, experience personal health and growth and live in the home of their choice and fully participate in their communities. To assess the degree to which Priority Outcomes reflect the OMRDD Vision, Focus Areas were categorized according to the priorities identified in the Vision Statement: Homes, Meaningful Relationships/Community Participation, Personal Growth, and Personal Health.

The information in Table D is organized as follows. The first column lists the Vision Statement priorities; the second identifies the corresponding Focus Area. The third column denotes the frequency that the Focus Area was cited as either the primary goal of a Priority Outcome or part of that Priority Outcome’s strategy. This data was obtained by using the filters “OMRDD Only” and “MR/DD disability only.” Data in the fourth column is based on an analysis of each Priority Outcome reflected in Column #3 and represents the percentage of Priority Outcomes that specifically target each Focus Area as a measurable goal.

TABLE D: Priority Outcomes Supporting OMRDD Vision

VISION STATEMENT: PEOPLE WITH DEVELOPMENTAL DISABILITIES WILL:	FOCUS AREAS	IDENTIFIED AS PRIORITY OUTCOME OR STRATEGY	TARGETED GOAL OF PRIORITY OUTCOME
LIVE IN THE HOME OF THEIR CHOICE	INCREASED ACCESS AND STABILITY IN HOUSING30%12%
ENJOY MEANINGFUL RELATIONSHIPS	INCREASED SOCIAL CONNECTEDNESS46%8%
EXPERIENCE GROWTH AND FULLY PARTICIPATE IN THEIR COMMUNITIES	INCREASE IN RETAINED EMPLOYMENT/MEANINGFUL ACTIVITY/EDUCATION22%6%
EXPERIENCE PERSONAL HEALTH	HEALTH & WELLNESS23%3%



Appendix D

Developmental Disabilities Services Offices

New York State Office of Mental Retardation and Developmental Disabilities

44 Holland Avenue
Albany, New York 12229
Information Line 1-(866)-946-9733
TTY: (866) 933-4889

Bernard M. Fineson Developmental Disabilities Services Office

80-45 Winchester Boulevard
Building 12
Queens Village, NY 11427
Phone: (718) 217-4242
Fax: (718) 217-4724
County Served: Queens
Director: Frank Parisi

Brooklyn Developmental Disabilities Services Office

888 Fountain Avenue
Brooklyn, NY 11208
Phone: (718) 642-6000
Fax: (718) 642-6282
County Served: Kings
Interim Director: Donna Limiti

Broome Developmental Disabilities Services Office

249 Glenwood Road
Binghamton, NY 13905
Phone: (607) 770-0211
Fax: (607) 770-8037
Counties Served: Broome, Chenango, Delaware, Otsego, Tioga, & Tompkins
Director: Patricia McDonnell

Capital District Developmental Disabilities Services Office

Oswald D. Heck Developmental Center
Balltown & Consaul Roads
Schenectady, New York 12304
Phone: (518) 370-7370
Fax: (518) 370-7401
Counties served: Albany, Fulton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, & Washington
Director: David Slingerland

Central NY Developmental Disabilities Services Office

101 West Liberty Street
Rome, NY 13442
Phone: (315) 336-2300
Fax: (315) 339-5456

Counties served: Cayuga, Cortland, Herkimer, Lewis, Madison, Onondaga, Oneida, & Oswego
Interim Director: John Gleason

Finger Lakes Developmental Disabilities Services Office

620 Westfall Road
Rochester, NY 14620
Phone: (585) 461-8500
Fax: (585) 461-0618
Counties served: Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, Wyoming, & Yates
Director: James Whitehead

Hudson Valley Developmental Disabilities Services Office

Hudson Valley DDSO
9 Wilbur Road
PO Box 470
Thiells, NY 10984
Phone: (845) 947-6000
Fax: (845) 947-6004
Counties served: Westchester, Orange, Rockland, & Sullivan
Director: Jill E. Gentile

Long Island Developmental Disabilities Services Office

45 Mall Drive
Commack, NY 11725
Phone: (631) 493-1700
Fax: (631) 493-1803
Counties served: Nassau & Suffolk
Director: Irene McGinn

Metro NY Developmental Disabilities Services Office

75 Morton Street
New York, NY 10014
Phone: (212) 229-3000
Fax: (212) 924-0580
Counties served: Bronx & Manhattan
Director: Hugh D. Tarpley, Ph.D.

Staten Island Developmental Disabilities Services Office

1150 Forest Hill Road
Staten Island, NY 10314
Phone: (718) 983-5200
Fax: (718) 983-9768
County served: Richmond
Director: David Booth, Ph.D.

Sunmount Developmental Disabilities Services Office

2445 State Route 30
Tupper Lake, NY 12986-2502
Phone: (518) 359-3311
Fax: (518) 359-2276
Counties served: Clinton, Essex, Franklin, Hamilton, Jefferson, & St. Lawrence
Director: Helene DeSanto

Taconic Developmental Disabilities Services Office

26 Center Circle
Wassaic, NY 12592
Phone: (845) 877-6821
Fax: (845) 877-9177
Counties served: Columbia, Dutchess, Greene, Putnam, & Ulster
Director: John Mizerak

Valley Ridge Developmental Disabilities Services Office

Serving individuals with intensive needs statewide.
Phone: (607) 337-7000
Director: Charles Kearley

Western NY Developmental Disabilities Services Office

1200 East & West Road
West Seneca, NY 1422
Phone: (716) 517-2000
Fax: (716) 674-7488
Counties served: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, & Orleans
Director: Bruce Korotkin

Institute for Basic Research in Developmental Disabilities

1050 Forest Hill Road
Staten Island, NY 10314
Phone: (718) 494-0600
Fax: (718) 698-3803
Director: W. Ted Brown, M.D., Ph.D.