

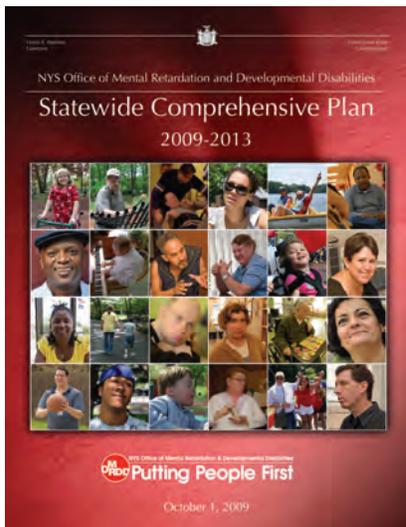


NYS Office of Mental Retardation & Developmental Disabilities

**Putting People First**

**Office of Mental Retardation and Developmental Disabilities**

# 2010 Interim Report



## 2009-2013 Statewide Comprehensive Plan



New York State  
David A. Paterson, Governor

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

**February 15, 2010**

## Background and Context

The Office of Mental Retardation and Developmental Disabilities (OMRDD) issued its Statewide Comprehensive Plan for 2009-2013 on October 1, 2009. This Statewide Plan set forth a commitment to “Putting People First,” and outlined the agency’s initiatives over a five-year horizon. This Interim Report, as required by Mental Hygiene Law §5.07, documents OMRDD’s actions in implementing its strategic imperatives, and reflects how the proposed OMRDD budget supports the agency Plan while meeting the State’s budget needs.

The close of 2009 completed a year of significant strides toward realigning OMRDD’s system to be more responsive to the needs of individuals and their families. In spite of a challenging fiscal environment, OMRDD has expanded service opportunities in a way that is increasingly individualized and person-centered.

OMRDD remains committed to its mission: *We help people with developmental disabilities live richer lives.* We do this by offering individuals high quality, fiscally responsible, individualized and person-centered supports and services to achieve four important outcomes consistently and poignantly articulated by self-advocates:

- Living in a home of their choice;
- Working or contributing to their community;
- Enjoying meaningful relationships, and
- Maintaining good health.

To support these outcomes, the Governor’s 2010-11 Executive Budget Recommendations for OMRDD will:

- Put people first by providing opportunities through individualized and person-centered supports and services within an environment of fiscal prudence and accountability while maximizing the number of available opportunities for people with developmental disabilities.
- Develop and maintain a diverse portfolio of residential and day services to support individuals and families.
- Promote interoperable solutions that require cross-system collaboration to address problems that occur on an individual, regional and/or statewide level.
- Continue a multi-year focus on funding rationalization and restructuring, which will result in efficiencies through both internal and interagency collaborative efforts.
- Enhance the capacity of our public and private-sector workforces and organizations, and strengthen our partnerships with people who have developmental disabilities, families, advocates and nonprofit agencies.
- Promote *Employment First* as a policy that affirms that people with developmental disabilities are part of New York’s workforce and labor strategy and is working with its partners to increase the number of individual who are competitively employed.



OMRDD will meet the challenges of 2010-11 in partnership with its stakeholders, including people with developmental disabilities, their families, advocates, and not-for-profit provider agencies to realize the values of equity, fairness, cost effectiveness and accountability in the use of resources.

This interim report on OMRDD's long-range plan for 2009-2013 provides an update on key initiatives and activities undertaken by OMRDD to realize its mission and achieve its strategic outcomes. The next section of the report demonstrates progress toward established goals and illustrates how the Governor's recommended budget supports the accomplishment of these outcomes. The reader is invited to revisit the OMRDD Strategic Framework for a brief overview of these goals at: [http://www.omr.state.ny.us/507plan/images/hp\\_507plan\\_stategicframework.pdf](http://www.omr.state.ny.us/507plan/images/hp_507plan_stategicframework.pdf)

See also the agency's Budget Briefing Book, which is being transmitted along with this report, for more specific information on Executive Budget recommendations.



## Progress Report

### People live in a home of their choice

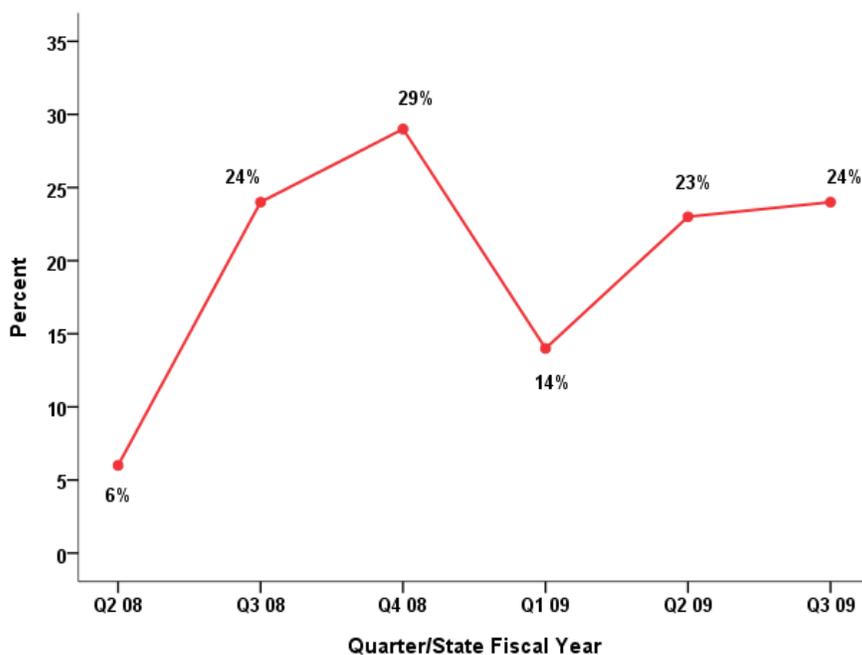
**Outcome:** Expand residential, day and at-home opportunities over the next five years through NYS-CARES III.

NYS-CARES is a nationally recognized program designed to address the out-of-home residential needs of individuals with developmental disabilities. Since its inception in August 1998 through March 31, 2010, NYS-CARES will have provided more than 17,000 residential opportunities.

OMRDD is committed to expanding the choices of living arrangements available to people with developmental disabilities. This effort includes expanding opportunities for independent living in non-certified homes and apartments with less than 24-hour staffing (referred to as supported living). Analyses indicate that a segment of people for whom residential supports are currently being sought, and even some presently served in 24/7 supervised settings, are capable of and would prefer supported living.

As the accompanying graph indicates, on average over the last 6 quarters, one out of every five community residential opportunities developed provided a supported living opportunity. This trend is expected to continue to grow into the future as more individuals choose these more independent living arrangements rather than the more highly supervised settings requested in the past. While this is clearly not an option for everyone and traditional supervised residential development will continue to be available for those who need it, OMRDD and its nonprofit service providers will increase efforts to support individual choice and self-determination in facilitating life decisions.

**Figure 1. Less than 24/7 Opportunities as a Percent of All New Residential Opportunities**

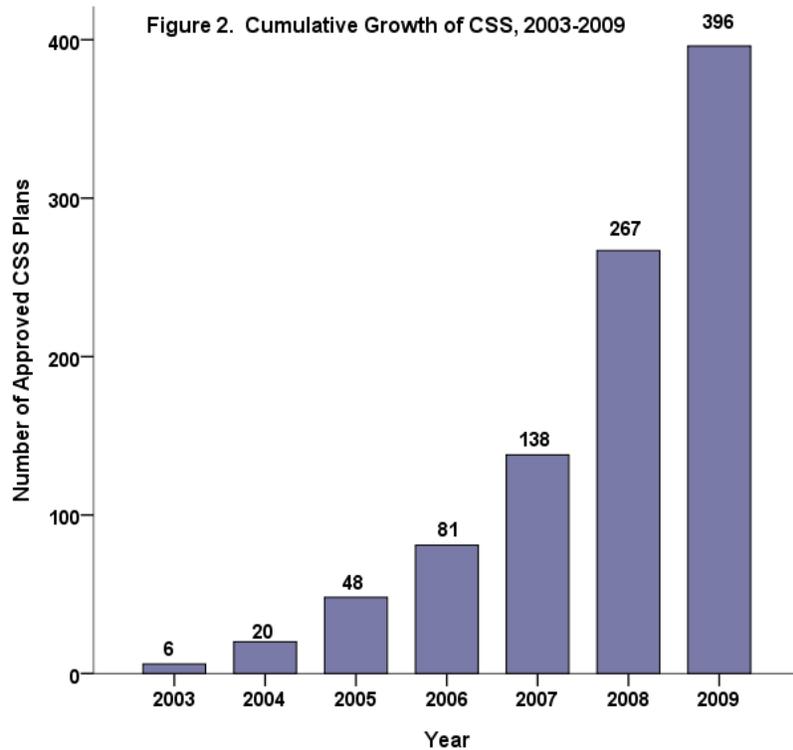


In addition to increasing opportunities for supportive living, OMRDD is also expanding innovative services through the Portal mechanism. The purpose of the Portal is to make the process of accessing

services provided through OMRDD more responsive to the needs and wishes of the individual seeking services. The Portal is not a service or a program. It is an attempt to design new methodologies and better practices for delivering the services people need. It is a learning opportunity where we can examine, challenge, and in some cases reinvent our current practices based on what we learn from this experience. The Portal process starts with the person first and encourages creativity and “thinking outside the box” to create the best plan for the individual. DDSO staff, in collaboration with individuals, family members, Medicaid Service Coordinators, and other members of the person’s circle of support, begin with a person-centered approach. The individualized service plan (ISP) and personal resource account (PRA) are individually tailored to support the person in realizing his or her life plan. Currently, the Portal provides funding for 130 opportunities, which may include a mix of residential and non-residential supports. The review and approval process is streamlined to encourage equity and timeliness. Individuals participating in the Portal have expressed their satisfaction with the services and the process. In addition, a majority of individual budgets were below the amount originally authorized by the PRA, illustrating the fiscal benefits of this new initiative.

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

The number of individuals accessing self-directed supports and services through the home and community-based services (HCBS) waiver, via Consolidated Supports and Services (CSS) continues to increase. CSS allows individuals, with the help of their circles of support, to self-direct the funding for their residential and/or day services. With the assistance of Fiscal Employer Agents (FEAs) and Support Brokers, individuals have successfully developed their own schedules, hired staff and managed their own services and supports. Since 2003, OMRDD has made considerable progress in expanding this option. Figure 2 illustrates this progress.



By the close of 2009, the CSS plans of 396 individuals had been approved and an additional 252 people were in the process of developing their CSS plans. Self-direction not only empowers people to exercise greater choice over their life, but also contributes to cost savings. Since the inception of CSS, OMRDD accrued an historical cost savings of \$2,544,598 compared with the projected cost of more traditional services for the participating individuals. In addition to the continuing progress with CSS, OMRDD is making more opportunities for self-direction available through At-Home-Residential-Habilitation (AHRH) and several new waiver services that will be added in the coming year. The desire for multiple

means to express self-direction is but one of the major themes that has become evident through our recent experiences with the Portal initiative.

### **People 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.

OMRDD is advancing its *Employment First Platform*, which is based on the premise that employment is the preferred outcome for all individuals with developmental disabilities. To advance this platform and increase the number of people who are working, the Center for Employment Excellence implemented several initiatives, including:

*Enhanced Supported Employment:* To date, 323 individuals with more significant needs are participating in supported employment and receiving enhanced services to help them obtain and sustain integrated employment. In fall 2009, participating providers initiated the evaluation component of the project and the first progress reports will be available in 2010. OMRDD anticipates that approximately 700 individuals will become successfully employed through this pilot project.

*Works for Me:* In partnership with our New York City employment providers, OMRDD hosted its second Works For Me event in Manhattan during October 2009. In addition to honoring employers who embody the agency's Employment First philosophy and their employees with developmental disabilities, new prospective employers in business and industry attended the event and heard stories of employment successes individuals have experienced.

*Pathways to Employment:* Included in OMRDD's HCBS waiver is a newly approved service to further the agency's Employment First philosophy. This new waiver service, time-limited and outcome-orientated, is designed to provide individualized supports for day habilitation participants to explore paid work. Currently, OMRDD is partnering with provider associations to complete the design of this new and very individualized path to employment.

OMRDD measures employment performance by tracking data through the New York State Interagency Employment Reporting System (NYSIER). Currently, 8,857 individuals with developmental disabilities receive OMRDD-funded employment supports statewide. Approximately 65% of these individuals maintained employment for one year or longer. OMRDD will advance the *Employment First Platform* and support people to become self-sufficient and competitively employed in jobs that utilize their knowledge, skills, and abilities.

### **People enjoy 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.

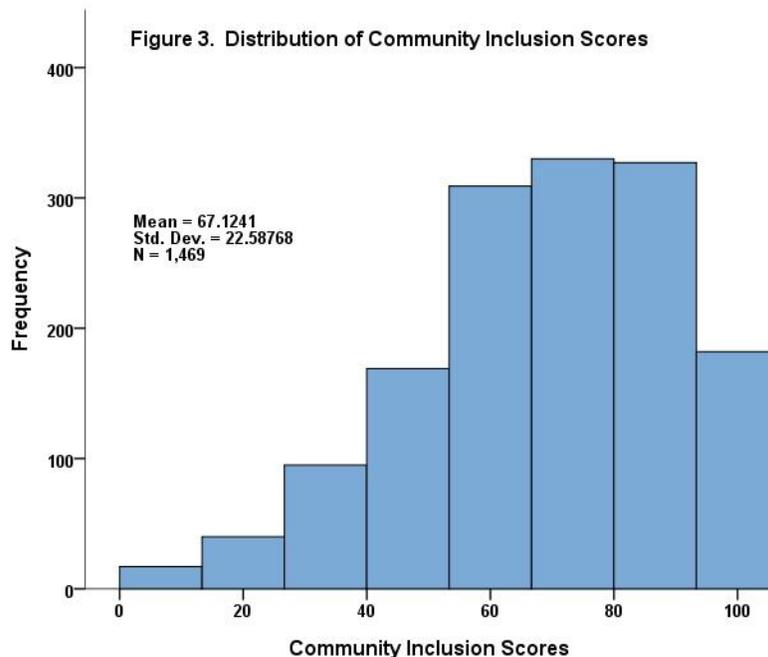
OMRDD continues to promote creative approaches to supports and services that will facilitate opportunities for meaningful relationships. There are two promising areas that will continue to get attention in the coming year. Shared living provides opportunities for a person with a developmental disability to share their home or apartment with another person with the expectation of shared responsibilities for routine household tasks and companionship. OMRDD is also working on an expanded and more flexible model of family care that we are calling “Family Care Too.” This approach allows people to invite a person with a developmental disability to share their home and experience meaningful relationships at the same time that necessary supports and services are available from the family or from other service providers.

To ascertain the level of community inclusion and the degree to which individuals enjoy meaningful relationships, OMRDD has begun tracking these important outcomes through the National Core Indicators (NCI) Project. NCI is a national project sponsored by the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS). State developmental disability agencies across the country participate in NCI to measure the performance of their state system and compare it to other participating states.

In 2008/2009, OMRDD administered the Consumer Survey, a face-to-face interview pertaining to quality of life and consumer satisfaction, to a representative sample of individuals receiving services in NYS. The survey included several questions that were used to construct a “community inclusion scale.” This scale included questions about monthly participation in shopping, errands and appointments, entertainment, restaurants, religious service/spiritual practice, and exercise. In addition, one item asked individuals if they went away on vacation in the past year.

As shown in Figure 3, scores near 100 indicate high levels of participation in the community activities cited above. People with a score close to 0 did not participate in these activities often. Scores in the middle indicate that people participate in only some of these activities. For the 1,469 individuals who responded to these questions, the mean community inclusion score is approximately 67.1 and the median is 71.4.

Quality of life for individuals with developmental disabilities is also significantly affected by the people they interact with on a day-to-day basis. Along with their friends and family, positive relationships with the staff who support them with daily activities are also crucial. OMRDD collaborated with the University at Albany School of Social Welfare and launched the Creating Connections Project in 2008 to





strengthen these essential relationships and thereby reduce instances of abuse, neglect, and serious reportable incidents. This project incorporates research and exemplary practices into curriculum and training for clinicians and direct support professionals. Creating Connections was successfully piloted in the Capital District DDSO and an “Assessment Toolkit” was disseminated in November 2009 to other regions of the State. The Toolkit will be used to assess the organizational culture of each DDSO and instill a culture of quality that will enhance relationships between individuals and staff.

**People experience personal health and growth**

**Outcome:** OMRDD will enhance the early identification, prevention, and treatment of health-related conditions for individuals with developmental disabilities.

Physical health and well-being are critical aspects of a person’s overall quality of life. One of the ways OMRDD assesses progress in this area is through data collected in the NCI project. Table 1 highlights responses to health indicators in the Consumer Survey 2008/2009.

**Table 1. NCI Health Indicators**

Indicator	Percent (%)
Annual Physical Exam	93.5
Six Month Dental Visit	67.1
Physically Active	55.8
Tobacco Use	7.3

Overall, a majority of individuals (93.5%) attend their annual physical exams and a small percentage (7.3%) of people chew or smoke tobacco products. The emphasis on health in the ISP process, as well as smoke-free state and voluntary facilities contribute to these positive outcomes. In the

Consumer Survey, “physically active” is defined as “engaging in moderate activity that increases breathing and heart rate.” Ultimately, the target for this survey item should approach 100%. In addition to exercise and physical activity, OMRDD continues to promote nutrition as a key aspect of preventing chronic conditions such as heart disease, diabetes, and obesity. OMRDD is in the process of adopting the American Dietetic Association’s state of the art Nutrition Care Process (NCP) to enhance clinical nutrition services to individuals with developmental disabilities. In early 2010, NCP will be piloted across the state to evaluate its application to daily clinical nutritional care.

Since the October 2009 issuance of OMRDD’s Five Year Plan, the State has dealt with a significant public health challenge in responding to the outbreak of H1N1 influenza (swine flu). OMRDD convened a response team of senior managers, stayed in close contact with public health officials at the NYS Department of Health (DOH), provided regular advisories to our providers through our Web site, facilitated the distribution of the vaccine, and developed new information technologies to track and respond to flu outbreaks in OMRDD programs. Our robust and aggressive response to the threatened pandemic underscored the agency’s commitment to positive health outcomes for the people we support. The experience has also served to test and improve our overall emergency and crisis response capacities.

OMRDD’s Institute for Basic Research (IBR) plays a vital role in the early identification, prevention and treatment of health and disability conditions. The Jervis Clinic at IBR is an important resource to the metropolitan New York area. In addition to the autism related research mentioned elsewhere in this report, IBR is conducting critical developmental disabilities research in other areas. Two examples of note:



- In recent months, IBR scientists reported the discovery of a new genetic mechanism that causes intellectual disability and abnormal brain development.
- IBR scientists received National Institutes of Health funding to accelerate the translation of low-frequency deep brain stimulation into a viable clinical therapy for partial-onset epilepsy.

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

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, which includes assisting individuals to make behavioral changes that lead to personal growth and a better quality of life.

Through the process of Functional Behavioral Assessment, a trained psychologist is able to investigate and communicate the processes underlying an individual's behavior and create effective strategies and supports to form the Behavior Support Plan. OMRDD clinical staff and Technical Assistance Team members have developed materials and presented training on Functional Behavioral Assessment to state and voluntary agency staff.

OMRDD is currently developing Communities of Practice for the clinical disciplines within the agency. Recognizing that clinical personnel often find it challenging to meet the unique and complex clinical needs of individuals, multiple training programs for clinicians were initiated. These trainings incorporate evidence-based best practices and are presented by experts in their fields.

OMRDD has reached out to other New York State agencies and invited their clinicians to participate in these and future trainings, which include presentations on treatment strategies and case consultations for individuals with developmental disabilities who are sex offenders. OMRDD is also actively collaborating with other state agencies to develop and present additional trainings on clinical topics of interest.

### **Themes Affecting All Services**

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

OMRDD continues to work with the Direct Support Workforce (DSW) Advisory Committee to address issues pertaining to direct support professionals. Through the activities of a grant funded by the Centers for Medicare and Medicaid Services (CMS), OMRDD has been able to research and identify exemplary practices to enhance the quality of the workforce.

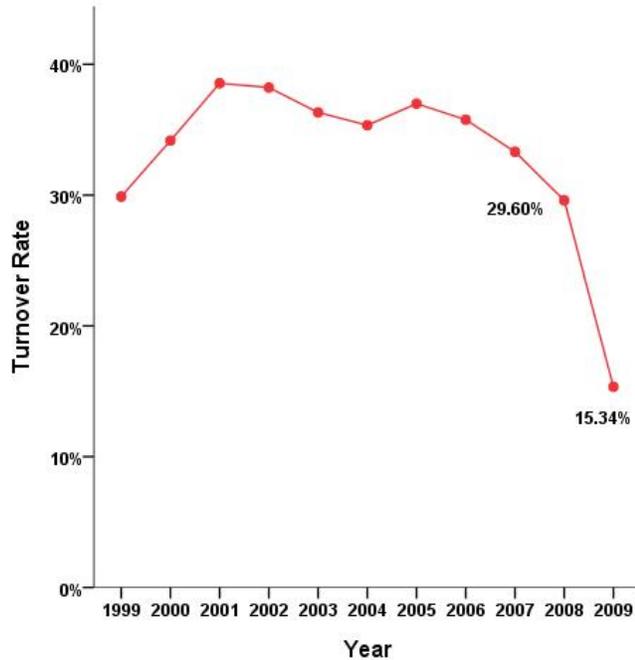
For example, the Division of Workforce and Talent Management tracks turnover rates in state operated programs as an indicator for workforce retention. As of November 2009, there were approximately 1,141 Developmental Aide Trainees across the state completing a one-year traineeship toward becoming



Developmental Aides. As indicated in the workforce literature, the highest levels of turnover tend to occur within one year of service, thus it is particularly important to track turnover for new employees. Figure 4 highlights the rate of turnover among this group over the past 10 years.

Generally, turnover rates fluctuated between 29.60% and 38.55% for Developmental Aide Trainees. In 2009, acknowledging the current economic conditions, the rate dropped significantly with a 50% decrease. OMRDD has reduced the use of overtime in its residential programs by improving management practices and closely monitoring staff schedules. This action has not only produced cost savings, but also improved the work environment for direct support professionals. It along with the previously mentioned Creating Connections Project and other DDSO based direct care initiatives may also contribute to the recent decline in turnover among these employees.

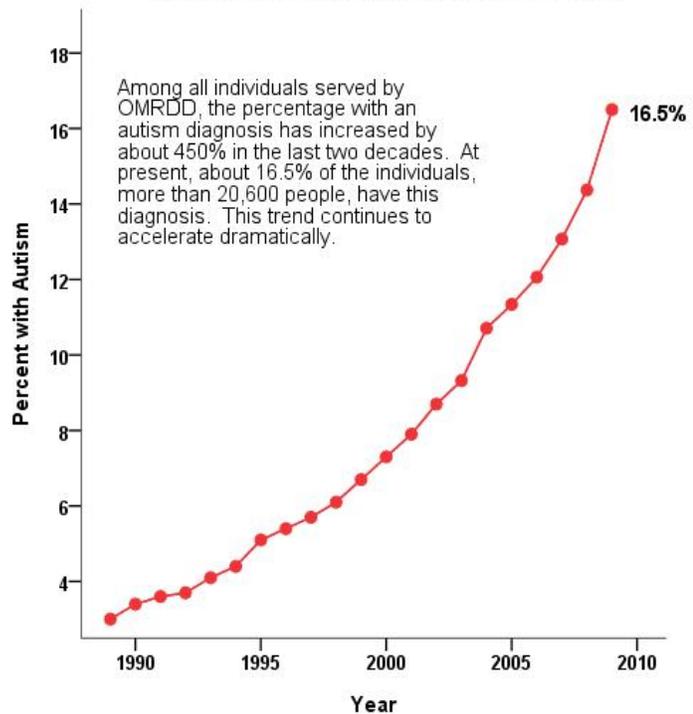
Figure 4. Developmental Aide Trainee Turnover: 1999-2009



**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.

The prevalence of Autism continues to increase nationwide. The most recent estimates from the Center for Disease Control and Prevention (CDC) <http://www.cdc.gov/> indicate that 1 in 110 children in the United States have an Autism Spectrum Disorder (ASD). There is also an upward trend in the number and proportion of individuals served by OMRDD who have an ASD diagnosis.

Figure 5. Individuals with Autism, 1989 - 2009



OMRDD established the Autism Platform in May 2008 to address the needs of individuals with ASD through a variety of different actions, which include:

- The Interagency Task Force on Autism

The Interagency Task Force on Autism, chaired by OMRDD and the State Education Department and composed of ten state agencies, completed its work and submitted its report to the Governor and Legislature, the Board of Regents, and the Inter-Office Coordinating Council. The Task Force examined five specific areas of need and made recommendations for how the needs can be addressed in both the short and long term. The five areas identified are: early identification of children with ASD; coordination of services across systems; adequacy and capacity of services; information dissemination; and coordination of research.

- Establishing a program for intensive assessment, treatment, and stabilization for adults with ASD

A specialized short-term residential program has been established on the campus of the former OD Heck Developmental Center. The program is tailored to meet the more intensive treatment needs of adults with autism whose behavior prevents their living in less restrictive settings. The clinical team reviews an average of two referrals per month and has successfully moved 12 individuals into less structured community-based settings.

- Standardizing guidelines for the screening, diagnosis and assessment of ASD

OMRDD has assembled an expert panel to complete a systematic review of existing but outdated best practice assessment guidelines; update the scientific research literature and information on which they are based; and issue clear guidelines that will assist NYS professional practitioners to understand and respond to the demand for careful screening and state-of-the-art assessment and diagnostic procedures related to ASD.

- Establishing the NYS Autism Consortium

The NYS Autism Consortium, composed of ASD experts, is moving forward to design, secure funding for, and carry out large-scale research studies, both basic and applied, and undertake statewide initiatives to improve our ability to serve individuals with ASD and their families. The research agenda encompasses the following priorities: training and education, treatment, early identification and intervention, and translational research.

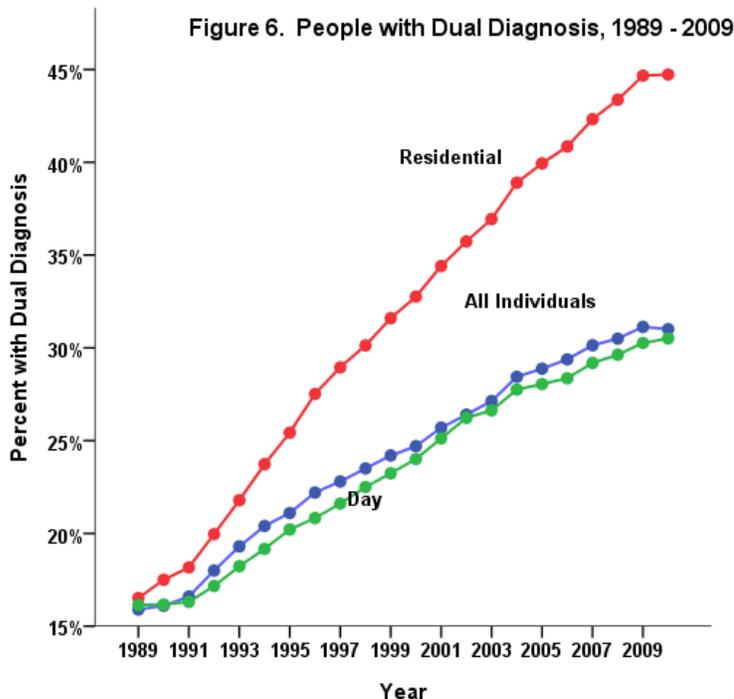
- Developing and distributing information on ASD and NYS Services

OMRDD has been sharing information about ASD through a brochure entitled *Facts About Autism and Finding Autism Spectrum Disorder Services*, and in web sites such as the Autism section of the OMRDD Web site and the NYS autism Web site, [nyacts.org](http://nyacts.org). Both media outlets provide the public with general information about ASD and service options available in NYS. In addition, OMRDD, in collaboration with the Interagency Task Force on Autism, will launch a public awareness campaign in 2010.

**Outcome:** Enhance services for individuals who have a dual diagnosis of mental illness and developmental disability through the development of collaborative agreements with the Office of Mental Health (OMH).

The number of individuals dually diagnosed with a developmental disability and a mental illness continues to grow. Across all services, over 30% of individuals served by OMRDD are dually diagnosed.

To address the needs of this special population, OMRDD has provided statewide resources and training activities that include videoconference training sessions on assessment and treatment based on functional behavioral assessment, as well as consultation, training and materials on the use of Dialectical Behavior Therapy (DBT), a specialized intervention for this population.



**Outcome:** Redesign the Quality Management survey process to promote an agency’s responsibility to self-monitor and improve the quality of its services. The revised review process will better promote the core values expressed in OMRDD’s vision and mission statements by increasing focus on individual satisfaction.

Following the fire at the Riverview IRA, in March of 2009, OMRDD undertook a review of its fire safety procedures, which included convening a Fire Safety Panel of Experts whose work resulted in recommendations to the Commissioner for improvements. OMRDD also created the Office of Safety and Security Services, which convened experts from around the state in a Community of Practice on fire safety issues that represents both state operations and voluntary providers. The Fire Safety Community of Practice has already provided guidance documents in the areas of Fire Drill Reporting, Evacuation Planning and Fire Safety Training that lay the groundwork for continued improvement. OMRDD has also formed a partnership with the NYS Office of Fire Prevention and Control (OFPC) to create and implement systems and controls that most effectively provide enhanced protections for the people served by OMRDD. It will continue to address the health and safety of individuals served and will be more effective in promoting individualized services, quality of life, choice, flexibility in service delivery, and agency responsibility for quality management. The process also makes more effective use of staff resources, reduces paper and mailing costs and allows for travel efficiencies. OMRDD expects to begin pilots of the revised process in April 2010.



The Division of Quality Management has developed eleven advisory panels throughout the state to discuss topics related to quality of services, quality of life, the survey process, and supporting and developing staff skills. These panels are comprised of DDSO staff, staff from not-for-profit provider agencies, individuals with developmental disabilities and their advocates.

OMRDD will continue to identify and implement improvements in the construction of facilities and the training of staff to ensure the safety of the individuals we serve.

**Outcome:** Enhance design of the Medicaid Service Coordination (MSC) program to ensure consistent provision of service to individuals with developmental disabilities.

The Informed Choice Design Team met monthly from May 2008 through December 2009 to develop the concept of informed choice in relation to service coordination and service delivery within the OMRDD system. The team included OMRDD Central Office staff, DDSO staff, voluntary agency staff, parents and self-advocates. An end product of the workgroup was the development of a conceptual framework for “Informed Choice” and a white paper that provides recommendations and guidance on the redesign of the MSC Program.

To assist service coordinators with managing paperwork and records, OMRDD created electronic versions of the ISP, DDP forms, Level of Care Eligibility Determination, and other MSC forms. These electronic forms will be tested by a small group of service coordinators in early 2010. It is anticipated that the MSC Electronic Record will result in efficiencies to the program.