



## Background and Context

On October 1, 2010 the Office for People With Developmental Disabilities (OPWDD) published its Update to the Statewide Comprehensive Plan. The Statewide Plan reiterated OPWDD commitment to “Putting People First,” and highlighted major priorities and initiatives throughout the State. This Interim Report, required by Mental Hygiene Law 5.07, documents OPWDD’s progress in implementing its strategic goals and aligns the proposed budget with the agency’s mission and vision:

### **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.*

Significant fiscal challenges remain with us in 2011. In his January 5th State of the State address, Governor Cuomo introduced a platform for creating efficiencies within State government. Consistent with the call for Medicaid Redesign, OPWDD is working side-by-side with self-advocates, family members, non-profit provider associations, and other state agencies to develop both short and long-term strategies to achieve cost savings and deliver quality services.

The next section of the interim report is a progress report highlighting OPWDD’s performance on key agency metrics pertaining to the “People First” areas. The performance measures were first discussed in the Update from October 2010. You are invited to revisit the Update to the Statewide Comprehensive plan for additional context. [http://www.omr.state.ny.us/507plan/images/hp\\_final507\\_2010-2014.pdf](http://www.omr.state.ny.us/507plan/images/hp_final507_2010-2014.pdf)



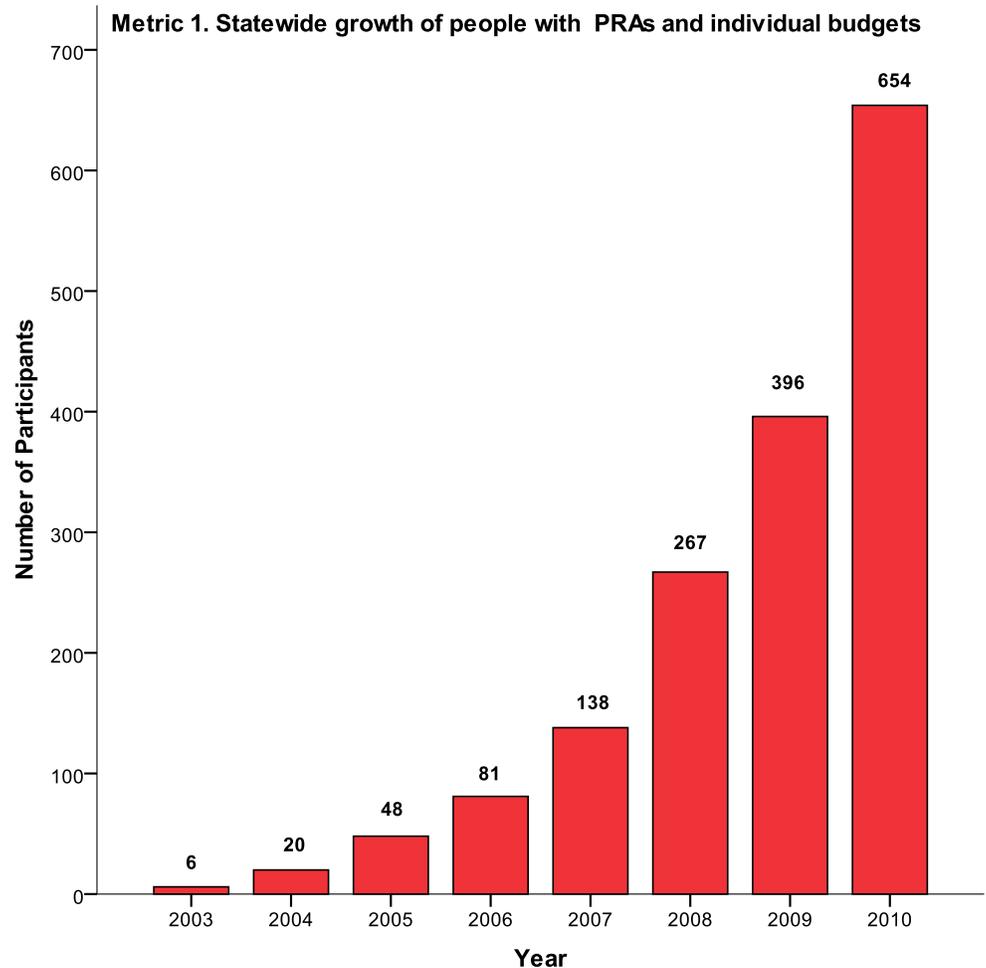
## Progress Report

### Putting People First: Person-Centered and Self-directed Supports

Since the publication of the Update to the Statewide Comprehensive Plan, OPWDD has been working on a new project called Individualized Supports and Services (ISS) with the goal of expanding opportunities for self-direction and individualized services across the State. Part of this endeavor involves exploring existing barriers to self-direction and promising new practices that can be integrated into the system. Eight workgroups are actively exploring service redesign issues related to personal resource accounts (PRAs) development, medication administration, budgeting guidelines, community transition, support brokerage, financial management services, informed choice training, and metrics.

OPWDD is measuring performance in this area by quantifying the number of individuals who have individualized budgets and personal resource accounts (PRAs). In previous years these were individuals accessing Consolidated Supports and Services (CSS). In 2010 people participating in the Portal and Learning Institute were added to the annual total shown in Metric 1.

As of December 2010, 654 people were utilizing PRAs and individualized budgets. In the upcoming years, these practices will be replicated and infused into the process for planning and developing new and existing services.



Another factor to consider when evaluating self-directed programs is satisfaction with the places people receive their supports, and the extent to which staff treat individuals with respect. OPWDD tracks satisfaction with self-directed services through indicators in the National Core Indicators (NCI) Consumer Survey. The Consumer Survey is a standardized instrument used to interview individuals with developmental disabilities and measures their satisfaction with services and quality of life. By participating in NCI, OPWDD can benchmark statewide performance and compare outcomes with other state developmental disability agencies. All metrics in the interim report that use data from NCI are based on interviews conducted during the 2008-



2009 data collection period (2009-2010 data is now being cleaned and finalized). Metric 2 contrasts the satisfaction levels of CSS participants and individuals receiving traditional services. Individuals in both settings responded positively to questions about their day, employment, and residential supports.

**Metric 2. Comparison of Satisfaction: CSS & Traditional Funding of Services**

For traditional services, people are happier with their day and employment settings than people receiving CSS, yet express a lower level of satisfaction regarding the place where they live. Interestingly, 100 percent of the individuals who self-direct their services feel that their staff treat them with respect. This outcome may be a result of the program design, as CSS participants are empowered to interview, hire and supervise their own staff.

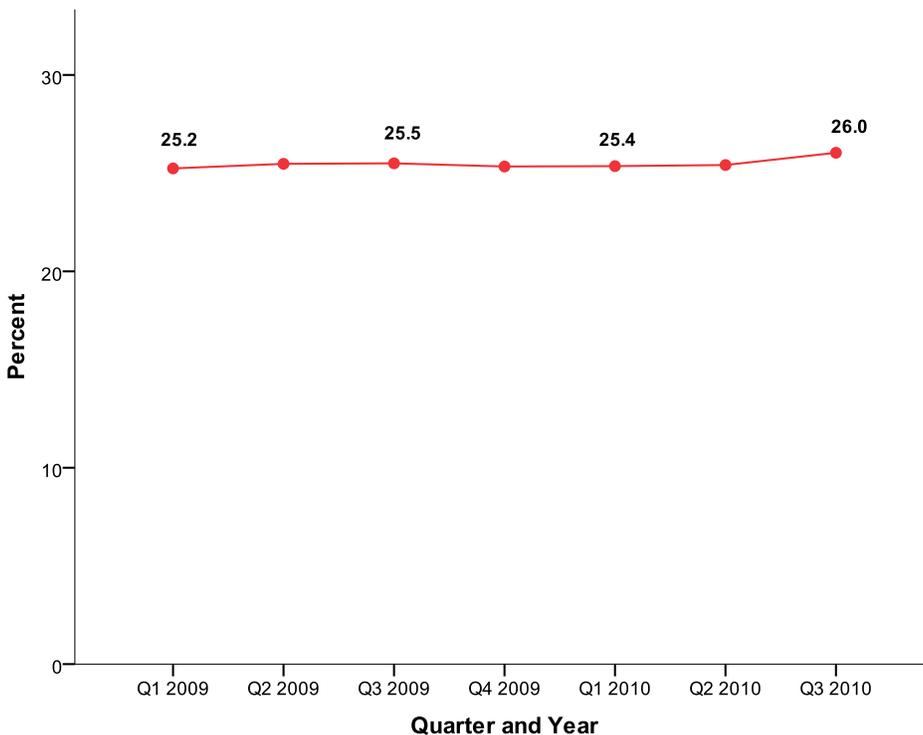
Indicator	CSS	Traditional
Likes Day Program	85.7%	87.5%
Day Staff are Respectful	100%	96.3%
Likes Job	85.7%	91.5%
Employment Staff are Respectful	100%	96.1%
Likes where he/she Lives	94.9%	89.9%
Residential Staff are Respectful	100%	96.2%

**People Live in their Home of Choice**

OPWDD is committed to helping individuals with developmental disabilities live in their home of choice, whether in their own home or in a residence operated by the State or a non-profit organization. One of the statewide goals is to support people in the least restrictive settings: those with less than 24 hour staff support. These environments include Supportive Individualized Residential Alternatives (IRAs), Supportive Community Residences (CRs), Family Care, Individualized Support Services (ISS) (rent subsidies to maintain

an independent living situation), and at home receiving Community Habilitation. Metric 3 shows the trend for people living in less restrictive settings.

**Metric 3. Percentage of People in a Less Restrictive Living Situation**



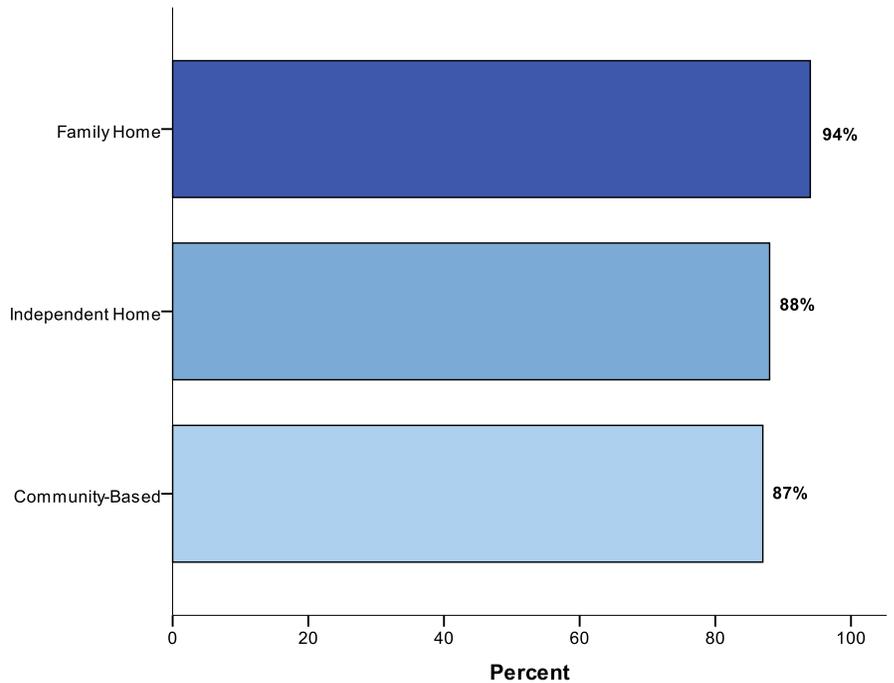
Over the year and a half span depicted, the percentage of people living in less restrictive settings has gradually risen to 26.0 percent. OPWDD will expand opportunities for people to access these types of living arrangements and continue the upward trend. As the agency improves its ability to support individuals in their own home or family home, people are more likely to have their needs met in a community-based setting.



Metric 4 compares individual satisfaction levels in three distinct residential settings: community-based, independent home and family home. The Human Services Research Institute (HSRI) defines community-based living situations as agency-operated residences where providers retain ownership of the property. In independent homes, the individuals either rent or own their home while a family home is owned by the individual’s parents or other relatives.

Overall, most people liked where they were currently living. Individuals residing with their families expressed the highest level of satisfaction (94%) while people in community-based and independent living situations responded nearly identically, though slightly lower than the statewide average of everyone who participated in the Consumer Survey (90%).

**Metric 4. Proportion of People who Like their Home by Setting**

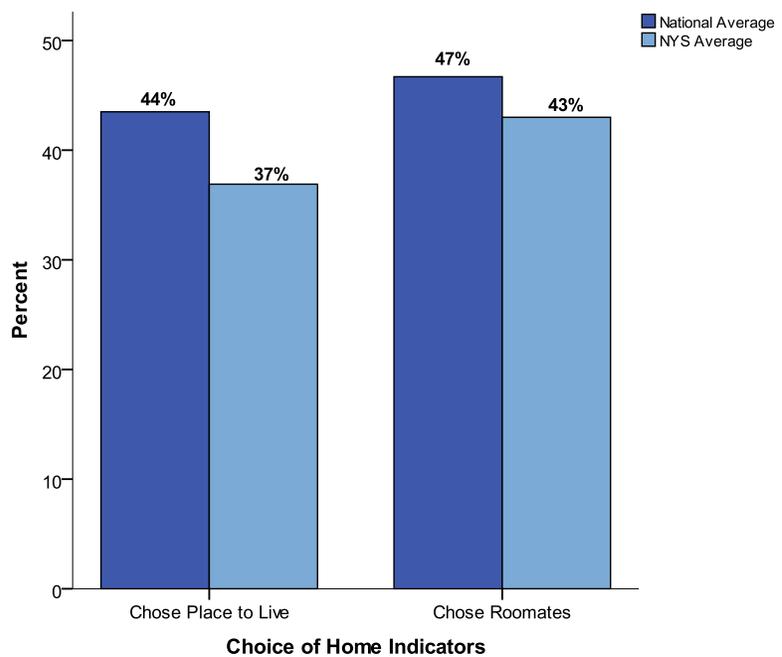


The ability to choose where and with whom one lives are also important indicators for satisfaction with home life. Metric 5 compares NYS with the other participating NCI states. For both indicators, NYS was slightly below the national average. OPWDD hopes to offer more opportunities for individuals to exercise choice over services and supports.

**Health**

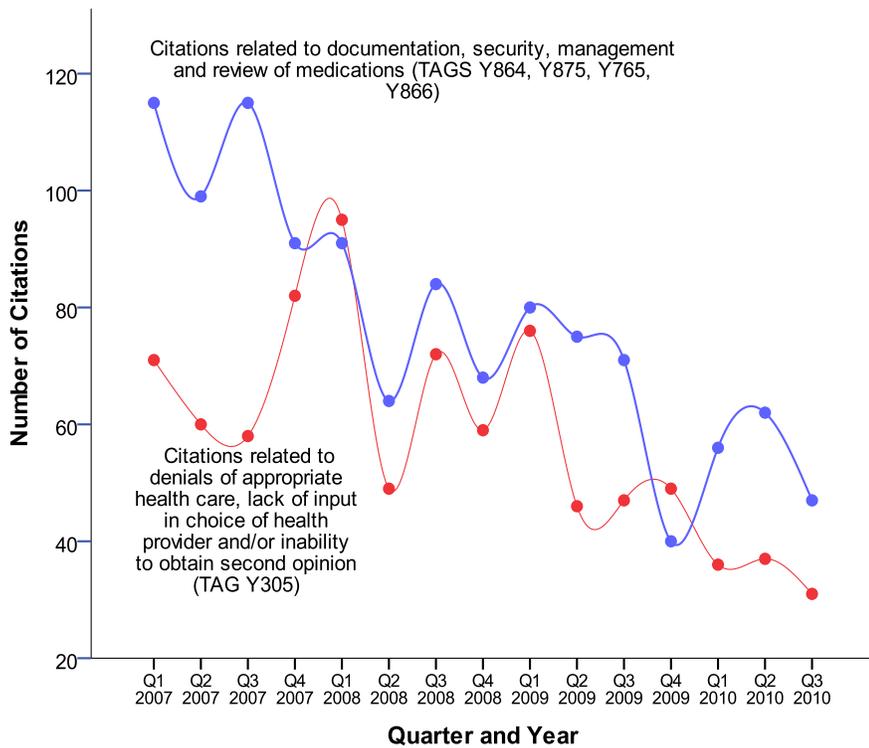
OPWDD strives to provide high quality health services to promote the physical well-being and behavioral health of individuals with developmental disabilities. In the past year the agency developed metrics to measure success in this area.

**Metric 5. People Chose their Roomates and Where they Live**





**Metric 6. Number of Health Related Citations**



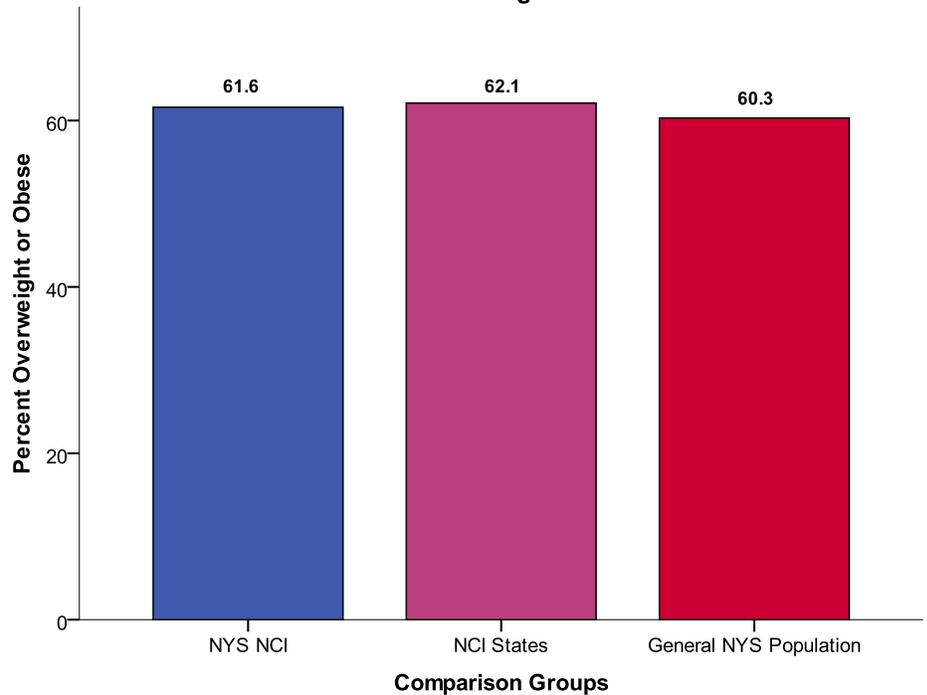
Metric 6 tracks the number of deficiencies that pertain to medication mismanagement and denials related to choice of health care provider and/or ability to obtain a second opinion. The blue line represents the sum of four factors related to medication mismanagement (inappropriate documentation, security, management, and/or review of medications) and the red line represents the number of deficiencies in health related choices. Over the past three years, both have trended downward, with denials of health related choices at an historic low.

Body Mass Index (BMI) is another important indicator of a healthy lifestyle. Obesity is a serious risk factor associated with chronic health conditions such as high

blood pressure, diabetes and heart disease. Through monitoring BMI regularly and developing interventions related to diet and exercise, OPWDD hopes to prevent the onset of chronic physical health conditions. Metric 7 is based on data collected from the NCI Consumer Survey (NYS and other NCI States), and general NYS population data collected by the NYS Department of Health.

Overall, the percentage of individuals with developmental disabilities in NYS who are overweight or obese (61.6%) is consistent with the national average of all participating NCI states, as well as the general NYS population. Obesity is a health concern for large numbers of people across the country.

**Metric 7. Individuals who are Overweight or Obese based on BMI**





## Work and Contribution

The objective of Employment First is to increase the number of people with developmental disabilities who are working in NYS. Many individuals could be successful in paying jobs with the appropriate level of supports, but for various reasons most individuals participate in other day programs. At the end of 2010, OPWDD supported 9,195 individuals in supported employment programs.

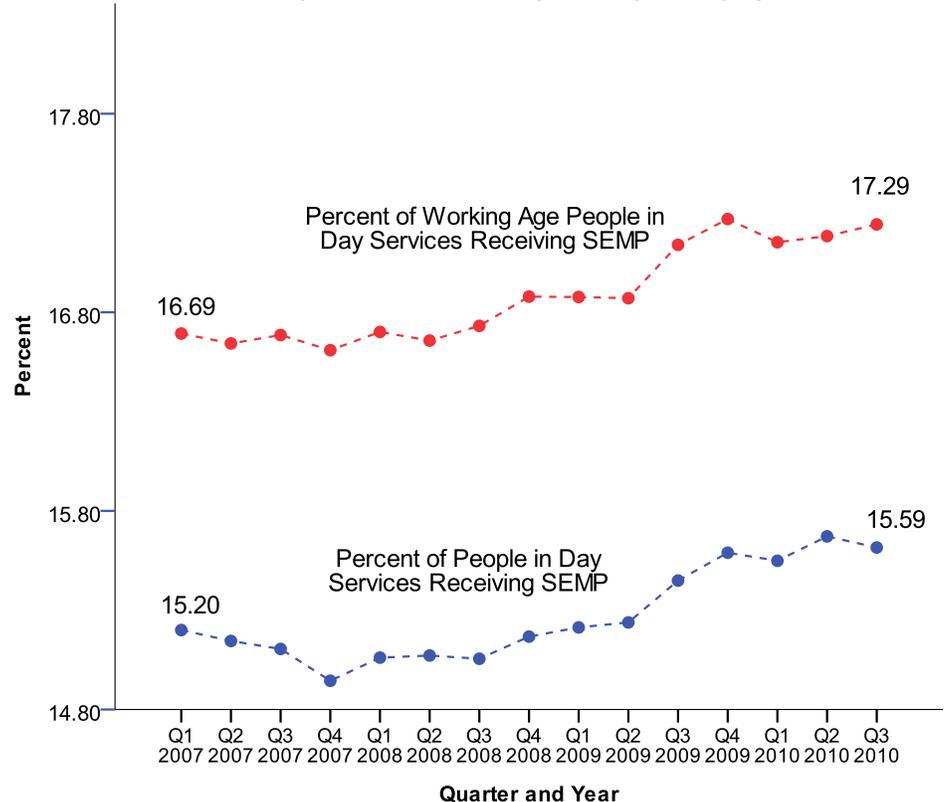
Enhanced Supported Employment (ESEMP) is one of the projects offering employment opportunities to individuals who would not likely succeed or qualify for traditional supported employment. Individuals receive greater levels of support, which could consist of person-centered planning, job development or job coaching. Currently, 405 individuals participate in ESEMP, with 259 individuals successfully working in the community. OPWDD anticipates that approximately 700 individuals will participate in this pilot.

OPWDD is collaborating with the NYS Office of Mental Health (OMH) on a federally funded Medicaid Infrastructure grant, *New York Makes Work Pay*. The purpose of the grant is to facilitate employment of people with disabilities through increased awareness and utilization of Social Security Work Incentives and Medicaid Buy-In Programs. As a result of this partnership, OPWDD will participate in an initiative that is designed to coordinate the collection of employment data and provide job leads to people with disabilities entitled the *One Stop Operating System*, available through the Department of Labor. This system will promote cross systems coordination of employment activities and supports, and increase opportunities for individuals to access job leads in real time.

Other employment initiatives include continuing development of the Pathways to Employment waiver service and the Employment Training Program (ETP), an 18 month paid internship program which leads to permanent employment in the community. At the close of 2010, ETP had grown to 300 interns.

OPWDD has developed indicators measuring the extent to which our service delivery system supports individuals who choose to work. Metric 8 trends the percentage of people enrolled in day services who receive supported employment (SEMP).

**Metric 8. People in Day Services Receiving SEMP (working age and all people)**





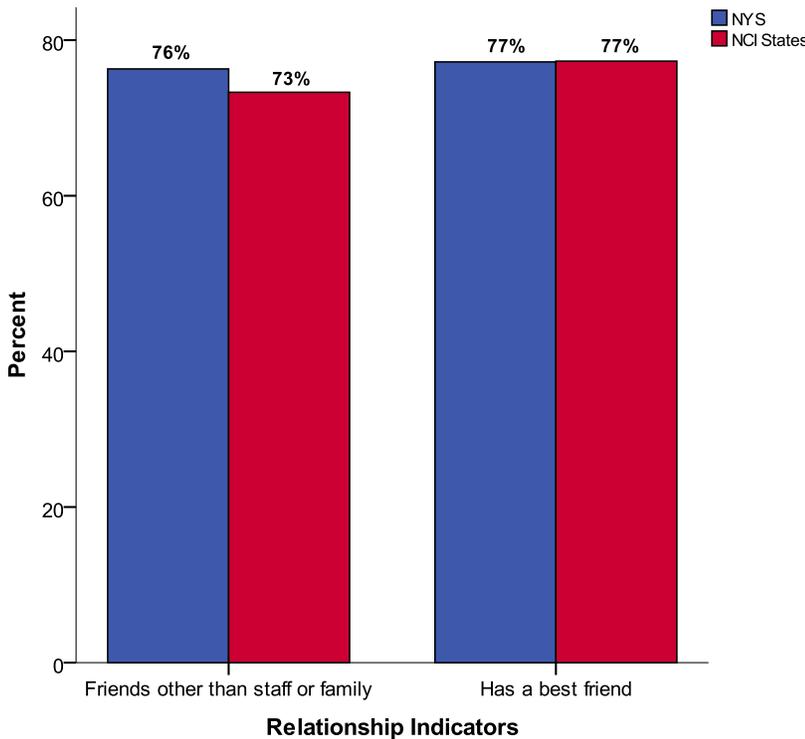
The red line represents people who are working age (23-64) and the blue line represents all individuals. As expected, individuals age 23-64 are more likely to be accessing supported employment services (17.29%). Overall the trend line has moved in a positive direction over the past three years, indicating progress with the Employment First Initiative.

## Relationships

Enjoying meaningful relationships with friends and family, and participating in the community are essential components to quality of life for individuals with developmental disabilities. With this goal in mind, OPWDD implemented the first part of a multi-phase roll-out of the Community Habilitation (CH) service on November 1, 2010. The first implementation phase converted the existing At Home Residential Habilitation (AHRH) service to the CH platform. This change established a framework to increase the menu of service options available to people in the Home and Community Based Services waiver. By making limited changes to the AHRH service provision rules, CH allows for increased flexibility in service design and greater community participation for individuals receiving services than was possible under the AHRH framework. This was accomplished by limiting the group size for individuals receiving the service to four people per CH worker and by no longer requiring that the service start, stop, or be fully delivered in a person’s home.

OPWDD is tracking outcomes related to relationships and community participation by measuring the extent to which people experience choice in community activities and the existence and quality of their relationships.

**Metric 9. Individuals Experience Meaningful Relationships**



Data for both of these indicators come from the 2008-2009 NCI Consumer Survey. Indicators for choice in community activities were integrated into the 2010-2011 data collection cycle, therefore data is not currently available for this metric. Metric 9 highlights individual responses to questions about having friends who are not staff or family members and whether or not they have a best friend.

Over three-quarters of the respondents to the survey either have a best friend or meaningful relationships with people other than their staff or family. In comparison to the other states participating in NCI, NYS scores either match or exceed the national average.



## Overarching Themes and Initiatives

### Institute for Basic Research in Developmental Disabilities

After participating in the largest randomized drug trial related to Fragile X syndrome, the Institute for Basic Research in Developmental Disabilities (IBR) is preparing to participate in additional clinical trials of promising treatments for developmental disabilities, which will include children and adults with Autism.

A team of IBR researchers have been collaborating on a study to establish criteria for the early diagnosis of Alzheimer's disease in individuals with Down syndrome. The findings may have direct implications for promoting more successful treatment and outcomes for adults with Down syndrome as they age, leading to earlier treatment. This program's earlier studies showed that risk for dementia among adults with Down syndrome was lower than expected in their 30s and early 40s, but increased substantially thereafter. They also showed that risk of Alzheimer's disease for adults with intellectual disability who do not have Down syndrome seems to be similar to that of the general population. The work will now undertake a variety of projects to extend the understanding of the onset and progression of Alzheimer's disease within the older population with Down syndrome.

### Medicaid Service Coordination (MSC) program

October 1, 2010 marked the effective date of a variety of changes related to the Medicaid Service Coordination (MSC) program. New OPWDD guidance documents pertinent to the MSC restructuring initiative have been issued and are available on the OPWDD website at: <http://www.omr.state.ny.us/wt/memoranda/index.jsp>.

The goal of the MSC redesign is to enhance flexibility while streamlining unnecessary paperwork or other requirements that do not bring value to individuals, and to keep this vital service fiscally viable during these challenging economic times. These changes are projected to bring about a \$30 million annual savings to the MSC program.

OPWDD has also enlisted the assistance of various stakeholders to help re-examine how MSC training is delivered throughout New York State. The workgroup is considering alternative training delivery methods and techniques to ensure that required training is made available to MSC's in a timely and cost-effective manner. To ensure that all individuals receive consistent high level quality service coordination, the workgroup is reviewing the needed skill sets for MSC's. These skill sets will be incorporated into appropriate training and professional development opportunities. Additional information will be forthcoming as plans are developed.

OPWDD has committed to evaluate the impact of the MSC redesign and to listen to feedback from stakeholders from across the State. A statewide MSC videoconference was held in December 2010 which offered opportunities for service coordinators and their supervisors to give their perspective on program changes. Surveys were also distributed to MSC vendors via e-visory. Initial feedback indicates vendors appreciate the greater flexibility and streamlined documentation, while the new unit allocation methodology and billing standards will take some more time to learn.

OPWDD is planning MSC listening forums beginning in the spring of 2011 to ensure that individuals, their families, service coordinators, and other stakeholders have the opportunity to share their experiences with the MSC changes. This feedback will be incorporated into the planning and design elements of the MSC program so it can continue to meet the needs of the over 70,000 people enrolled.



As a component of the agency's Quality Management Strategy, OPWDD has developed a revised approach for the review of MSC services. The revised protocol includes quality indicators that measure the program's impact on individualized outcomes such as building natural supports and community relationships, promoting informed choices, and individual satisfaction with MSC services. The data collected will allow OPWDD to evaluate the quality of services provided by a single MSC vendor and also the statewide system as a whole. The revised MSC review protocol is based on recommendations made by a committee comprised of self-advocates, advocates, OPWDD, provider agency representatives, and other stakeholders and members of the Real Choice committee charged with focusing on quality indicators. OPWDD will begin to pilot the MSC protocol in spring 2011 and will evaluate its effectiveness based on data collected during the first six months of implementation.

## **Autism Spectrum Disorders (ASDs)**

In 2010, OPWDD issued a revised Autism Platform to reflect the findings and recommendations of the Autism Task Force. The updated Autism Platform organizes the many OPWDD and multi-agency initiatives and activities that are now underway according to the following four priority themes, each of which will enhance New York State's ability to effectively and appropriately support citizens living with ASD:

### **1) ASD Training**

Since the 2010 5.07 Plan, OPWDD has continued advanced several autism training initiatives. The agency has continued to participate in the Developmental Disabilities Planning Council and Niagara University's development of statewide Disability Awareness Training for New York's first responders, assigning four DDSO staff representatives to assist with the project. OPWDD also developed and launched its new parent training program, "Targeting the Big Three" and trained 50 trainers to deliver evidence-based behavior intervention training to parents and caregivers working with individuals with autism and other developmental disabilities. In addition, OPWDD and voluntary agency staff piloted a new ASD staff training curriculum developed at Binghamton University's Institute for Child Development; the new curriculum should be finalized early this year. OPWDD anticipates making this training available throughout its statewide system.

### **2) Sharing Information**

OPWDD has continued to work with other State agencies to expand the New York State online autism resource, NYacts ([www.nyacts.com](http://www.nyacts.com)) and guide the multi-agency ASD public awareness campaign recommended by the New York State Interagency Task Force on Autism. Together with eight other State agency partners, OPWDD has helped to inform staff within nine agencies and their respective external stakeholders about ASDs, the need to identify children who may be at risk, and how to contact New York State agencies for services and supports.

### **3) Improving the Service System**

OPWDD has experienced significant success delivering clinical behavior intervention services to students in public schools in New York City through collaboration with the New York State and City Departments of Education. These services have enabled students whose behavioral challenges had threatened their public school placement to remain in school. Also, under OPWDD leadership an expert panel was assembled to establish standardized guidelines for the assessment and diagnosis of ASDs. The panel is now drafting their guidance document.



#### **4) Advancing Scientific Understanding**

Scientists and researchers at OPWDD's Institute for Basic Research in Developmental Disabilities (IBR) continue to pursue a wide ranging slate of basic and applied studies with significant implications for future treatment of ASDs. In addition, the New York State Autism Consortium, spearheaded by OPWDD's Autism Treatment Lab at IBR, has begun exploring the possible creation of "laboratory schools" that would support individuals with ASD diagnoses with state-of-the-art interventions while providing applied research capacity to further grow the evidence base for best practices.

### **Workforce Development**

#### **Direct Support Workforce (DSW) Advisory Committee**

The Direct Support Workforce (DSW) Advisory Committee is the stakeholder group charged with addressing workforce issues related to Direct Support Professionals (DSPs). The goals and objectives of the committee are to:

- Address issues of recruiting and retaining a high quality workforce;
- Develop DSP job design and career development recommendations;
- Assess workforce capacity, regional differences and cost impacts, particularly for high-need individuals and underserved geographic areas; and
- Develop a plan to address future workforce needs.

Members of the DSW Advisory Committee have been working with a consultant on identifying information and direction on NYS DSP workforce issues. Within the next four months, they are expected to provide OPWDD with: (1) useful insight from previously collected data on workforce development; (2) a review and analysis of national market research on staffing, recruitment, and retention; (3) an assessment of NYS workforce capacity needs; and (4) recommendations for improving data collection and addressing future workforce needs in State and Voluntary programs throughout NYS. The DSW Advisory Committee continues to meet on a quarterly basis.

In 2011, OPWDD will undertake an initiative designed to develop a common set of competencies for all Direct Support Professionals in the service delivery system (state and voluntary). This effort will engage all major stakeholders and partners and will involve members of the DSW Advisory Committee.

#### **Talent 2020 Platform**

As part of the Talent 2020 Platform, OPWDD is embarking on an ambitious and comprehensive project to develop a consistent, enterprise-wide approach to delivering training to the Direct Care workforce. Developing a cohesive, standardized approach to the delivery of training programs will bolster our commitment to the workforce and result in even better outcomes for the individuals we serve. Appropriate outcome measures will be developed to track the impact of the new training methodology on the effectiveness of services provided and on the morale of the workforce.

#### **Creating Connections**

The initiative that OPWDD has introduced statewide to all DDSOs with the purpose of fostering effective relationships within our system is called *Creating Connections*. Implementation of the initiative has already begun taking place throughout the State following a successful model developed at Capital District DDSO. In 2008, the Capital District DDSO worked with the Center for Excellence in Aging Services (School of Social Welfare, University at Albany) to conduct a study with direct care and clinical staff. The study was titled



"Creating Connections: Focus Group Findings with Direct Care and Clinical Staff at the New York State Office of Mental Retardation and Developmental Disabilities." The School facilitated focus groups, asking staff to discuss several questions pertaining to the work they do and the challenges they face every day on the job. Groups were broken down into direct staff, clinicians, and supervisors; individuals in care and family members were also involved. Results included increased job satisfaction by staff, increased positive relationships between staff and individuals they serve, and a substantial reduction in the number of negative outcomes for people.

As a result of the initiative's success at the Capital District DDSO, all OPWDD field offices will go through a similar evaluation process with the goals of fostering and enhancing effective communication at all levels of facility staffing and strengthening positive relationships between our employees and the individuals that we support.