David A. Paterson
Governor

Max E. Chmura
Acting Commissioner

NYS Office For People With Developmental Disabilities

Statewide Comprehensive Plan

2010-2014

NYS Office For People With Developmental Disabilities
Putting People First

October 1, 2010

NYS Office For People With Developmental Disabilities
OPWDD Putting People First

David A. Paterson, *Governor*
Max E. Chmura, *Acting Commissioner*

Executive Office

44 Holland Avenue
Albany, NY 12229-0001

TEL: 518-473-1997
FAX: 518-473-1271
TTY: 866-933-4889

www.omr.state.ny.us

October 1, 2010

Dear Friends and Colleagues:

It is with great pleasure that I share with you the New York State Office for People With Developmental Disabilities Statewide Comprehensive Plan for the period of 2010-2014.

As you are aware, the NYS Legislature recently passed the bill to remove "mental retardation" from the agency name: a top priority for the administration since 2007. This historic legislation could not be accomplished without the support of self-advocates, family members and the provider community. As a result of your advocacy and hard work, citizens in NYS will be referenced with the respect and dignity they so rightly deserve.

The agency name change is just one example of how we can make significant progress despite the precarious fiscal environment surrounding us. Although the economic recession will affect the ways we have traditionally done business, I am confident that OPWDD and its network of nonprofit providers will continue to provide quality services and supports to individuals with developmental disabilities and their family members. I ask you to view the current environment in NYS as a challenging opportunity for action with innovative approaches to service development and delivery.

As you read through the plan, you will learn about our progress and future plans on key initiatives related to our major goals and priorities. These range from work on our Autism Platform to the implementation of Enhanced Supportive Employment to the creation of Intensive Behavioral Services. It also encompasses comprehensive efforts to increase our system's overall capacity to respond to people's desires for more individualized supports and services. In this regard, the plan includes updates on our Portal Initiative and our agency-wide efforts to simplify business practices to help individuals more easily access these supports and services.

Over the past 30 years, our agency successfully developed the infrastructure for 24/7 residential opportunities. Now our goal is to maintain the current residential capacity and "balance" our portfolio of services through expansion of less restrictive residential opportunities. The environment and demographics of our population are changing and it is important for us to listen and respond to individuals' specific needs and wishes for the future they envision.

This plan is stronger for the input we received during its development, specifically individuals who participated in the Public Hearing and online planning survey, and the counties who communicated their priorities through the interagency County Planning System. For that continued guidance and input I am very grateful.

On behalf of the entire Leadership Team of OPWDD, thank you to all staff in the state and nonprofit workforce who support individuals with developmental disabilities to live richer lives. This plan lays out a daunting agenda that we hope both acknowledges the importance of the work you do everyday, and commits OPWDD to strengthen the tools you have to succeed in this important work.

Finally, this plan is dedicated to the citizens of New York State with developmental disabilities and their families. You encourage, inspire and hold us accountable each and every day.

Sincerely,

Max E. Chmura
Acting Commissioner

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The Office for People with Developmental Disabilities (OPWDD) is pleased to present this Update to its Comprehensive Plan for 2006-2010. In the following pages you will find OPWDD's guiding principles, descriptions of key activities, progress on those activities and directions for the future focused on helping people realize their personal goals related to home, community contribution, relationships and health. OPWDD plays several roles as it seeks to be responsive to the needs and wishes of individuals with developmental disabilities, and their families and advocates. As the state agency responsible for the developmental disabilities service system, OPWDD is the funder, regulator and overseer of supports and services provided by an array of not-for-profit providers, as well as a direct provider of services. In addition, OPWDD seeks to identify and embrace advances in treatment and best practices in service delivery as well as breakthroughs in prevention and treatment made possible through the work of its internationally recognized Institute for Basic Research in Developmental Disabilities (IBR). The work of OPWDD begins with the people to whom it is dedicated, to helping them realize their goals and dreams and supporting each person to live the life they want. This Update focuses on major initiatives where OPWDD experienced growth within the last year. For information on other equally important agency priorities, please see the agency's website at www.omr.state.ny.us.

Chapter 1: 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, OPWDD 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 OPWDD Comprehensive Plan Update for 2006-2010 (as they have the Plans, Updates and related Interim Reports since 2007). Associated with these outcomes are performance measures through which we will track how well we are achieving our goals. The National Core Indicators (NCI) project is part of an ongoing dialogue between OPWDD and the people we serve to determine what works and what needs to be modified. The NCI Consumer Survey consists of a standard set of nationally developed performance measures used by states to manage quality and assess progress toward benchmarks. OPWDD has chosen to make the NCI data part of a metrics-based quality management system

that captures the extent to which OPWDD'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 New York State (NYS). See Appendix B for more information on NCI.

Values

Values describe how we as employees of OPWDD 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 OPWDD 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 - OPWDD'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. OPWDD 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. OPWDD 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.

Responding to the Call for Change

The agency that was known for more than thirty years as the Office of Mental Retardation and Developmental Disabilities (OMRDD) this year experienced one of its proudest moments. Responding to the wishes of the people it supports and their families and advocates, and in keeping with its own mission and values, the NYS Legislature passed and Governor Paterson signed into law his Governor's Program bill changing its name to the Office for People with Developmental Disabilities (OPWDD). The new name is emblematic of OPWDD's commitment to putting people first and the embodiment of its mission, vision, values and guiding principles, and all that we have accomplished since the closing of Willowbrook State School.

The name change also signals the ongoing sea change at OPWDD, streamlining funding and business practices, creating greater flexibility in the design and delivery of services and promoting greater control and independence on the part of individuals, all focused on helping each person live the life they want.

This Comprehensive Plan Update for 2010-2014 is a progress report on key activities and initiatives established in earlier Plans, as well as descriptions of new projects and initiatives that further the OPWDD agenda and realize its mission to help people with developmental disabilities live richer lives.

Although our primary customers are the individuals and families who count on us, no less important is the well-trained and dedicated workforce. These dedicated people enable us to realize our vision, families to support their loved ones at home and individuals to live out their dreams and ambitions. Direct Support Professionals are vital to all that we do and should continue to receive the attention they deserve as we meet budgetary challenges, plan and execute training, and support them in their invaluable contribution to our mission.

Despite, and even stimulated by the current fiscal situation in NYS and attendant pressures on OPWDD, its not-for-profit agency partners and, most especially the individuals and families who rely on developmental disabilities services, OPWDD is creating new and better ways to make these supports available. In the pages that follow, you will find essential information about OPWDD and the developmental disabilities service system in NYS as well as descriptions of some of the work of which we are most proud.

Chapter 2: Eligibility and Demographics

Developmental Disabilities

The rules that guide OPWDD's work is the NYS Mental Hygiene Law (MHL); which tasks the agency with furthering the prevention and early detection of developmental disabilities and with providing a system of services to individuals with developmental disabilities. Section 1.03(22) of the NYS Mental Hygiene Law defines developmental disability and is the basis for determining eligibility for OPWDD-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; or

(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 OPWDD-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 disability diagnosis.

To increase the quality and consistency of eligibility assessments and awareness of the eligibility process and standards, OPWDD issued the following guidance: *OPWDD 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 OPWDD website (www.omr.state.ny.us) making them available to individuals, families, providers, and clinicians alike.

Prevalence of Developmental Disabilities

Pending the publication of data from the 2010 census, the following summary relies upon data from a widely accepted NYS population projection from the U.S. Census Bureau's 2006 estimate of the NYS population of 19,306,183. Using 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. Recent studies indicate a national rise in the number of people diagnosed with an Autism Spectrum Disorder (ASD), particularly children. However, uncertainty about its prevalence and the potential impact of this on the prevalence of other related developmental disabilities continues. OPWDD is reviewing prevalence estimations and will address the issue in greater detail in future plan updates. Until then, the best estimate is that over 300,000 people living in NYS have at least one developmental disability.

Table 1 shows estimates of the prevalence of developmental disabilities in the population of NYS, based on a model derived from the professional literature and used in OPWDD's past plans. As noted above, the total population is based on the NYS general population projections from the US Census Bureau's 2006 estimates. The only substantive difference from past estimates is the autism rate. Recent ASD research findings contribute to the increased prevalence estimate. Many biological and environmental factors have also been suggested for this increase, but changing clinical criteria, better case finding, early detection, improved access for young children to diagnostic services, and better training of diagnosticians likely account for some part of the higher estimate. It is important to stress that although this table shows, for example, that 279,589 people are estimated to be diagnosed with mental retardation, many of these same people may be diagnosed with cerebral palsy or epilepsy. Because of cases of multiple disabilities, the total number of instances of these conditions is higher than the total number of people affected.

Table 1. 2006 Prevalence estimates (conditions) for categorical developmental disabilities as defined in the New York State Mental Hygiene Law

Disability Conditions	Number of Affected People	Population Percentage Affected	Rate per 1,000 people
All Instances of Autism	165,946	0.861%	8.61
All Instances of Cerebral Palsy	25,838	0.134%	1.34
All Instances of Epilepsy	21,981	0.114%	1.14
All Instances of Mental Retardation	279,589	1.450%	14.50
All Instances of Neurological Impairment	36,057	0.187%	1.87
Total People Affected	444,176	2.304%	23.04

Autism estimates are based on estimates for 2006 from the Autism and Developmental Disabilities Monitoring Network (Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders - Autism and Developmental Disabilities Monitoring Network, United States, 2006. Surveillance Summaries, December 18, 2009. MMWR 2009;58(No. SS-10)) and have been adjusted for the demographic composition of New York State.

The people we support

OPWDD supports a diverse, growing and changing group of individuals and families. Figures 1 and 2 illustrate two fundamental aspects of this diversity.

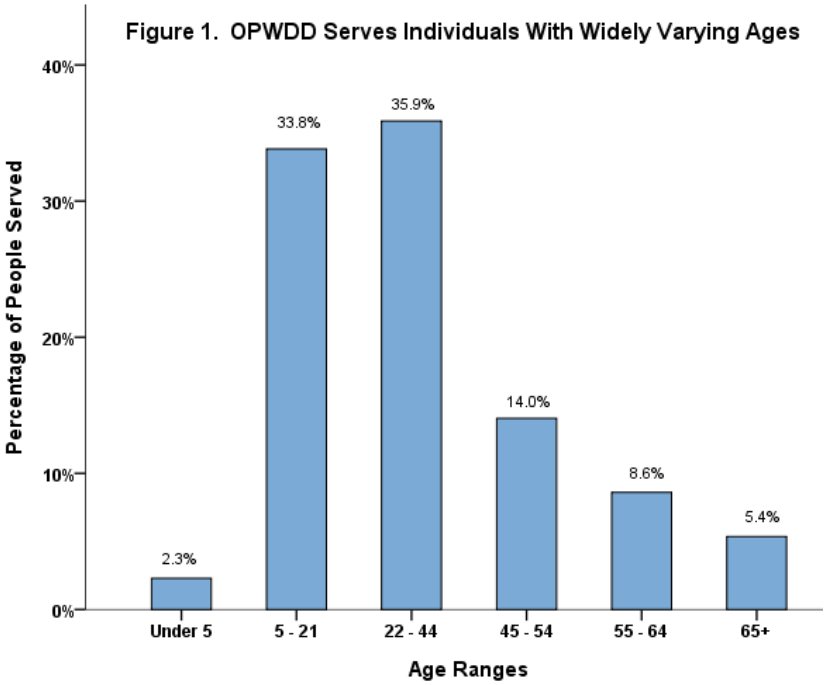


Figure 1 shows the distribution of age among all individuals receiving supports and services through OPWDD. The age range is great, from near birth to people who have lived into their 90s, reminding us that services must be developed that are sensitive to the differing needs of this broad age spectrum.

More than a third of the individuals supported by OPWDD's service system are under the age of 22, a constituency with unique age-related issues and needs that in some measure has served to refocus OPWDD's services and supports. The largest group is comprised of 22-44 year olds (35.9%), and is a negligibly smaller portion than in the last annual plan. All other age groups have also

seen little change in size in that time; an exception to this is that more than one-fourth of the individuals served are 45 or older, up more than 10% since 2004 and a major driver of services.

A second major point of diversity among the individuals supported is cultural diversity related to race and ethnicity. This diversity is growing as OPWDD reaches out to cultural communities and multicultural providers to identify and meet the need for services. Figure 2 describes broadly the multicultural distribution of people supported by OPWDD. OPWDD serves an increasing array of ethnic groups in this large and extremely diverse state, and is eager to address their needs in a culturally aware and competent way. As Figure 2 shows, nearly 40% of individuals served are from a federally defined racial or ethnic minority group. Overall, the diversity of the people we serve is roughly proportional to New York's general population. Further, the multicultural representation among the people served has been steadily rising, increasing by over 10% in the last decade as OPWDD is successful in reaching all cultures and communities.

Figure 2. OPWDD Serves a Diverse Population

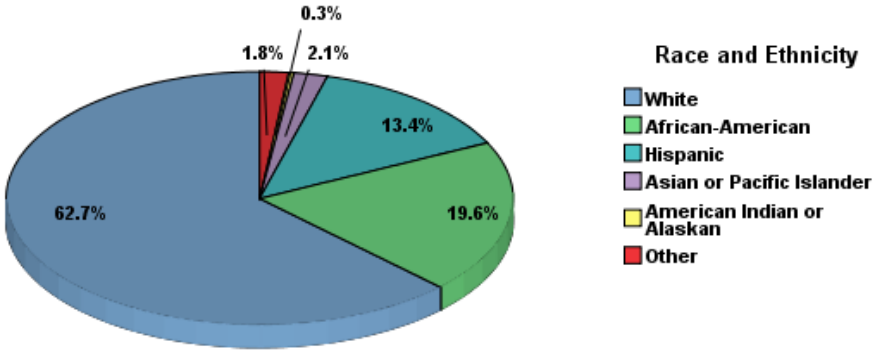
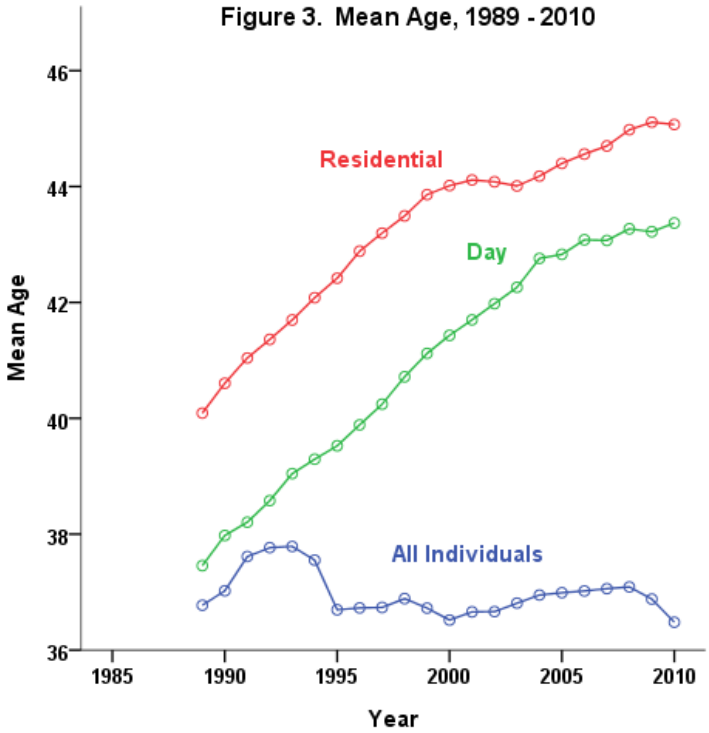


Figure 3 shows the age trends for three groups: all individuals (an unduplicated count of people getting any type of service from OPWDD), people living in an out-of-home residential setting and individuals participating in day activities. This shows clear upward trends in aging for both residential and day participants, and at roughly the same pace. People living in residential settings lead this trend, with the mean (i.e., average) age increasing from around 40 in 1989 to almost 45 in 2009. Sometime in the next 20 years the mean age among individuals living in an OPWDD residential setting will reach 50 years of age. The likely continuation of this longstanding trend will have major implications for the support levels required in these settings.

Figure 3. Mean Age, 1989 - 2010



Over the thirty years of the agency's existence, the diverse and changing needs of individuals and families have driven the expansion and reconfiguration of the services and supports provided.

Because individuals typically get several types of services and supports, the three groups in Figure 3 are overlapping (i.e., some people are part of both the residential and day services groups). However, Figure 3 also indicates that among all individuals participating in OPWDD services and supports there is little evidence of an overall system age trend. (It must be noted that the *All Individuals* category represents an unduplicated count of people getting any type of service from OPWDD requiring a completed Developmental Disabilities Profile (DDP-2). Currently, there is a range of supports and services for which the DDP-2 is not required).

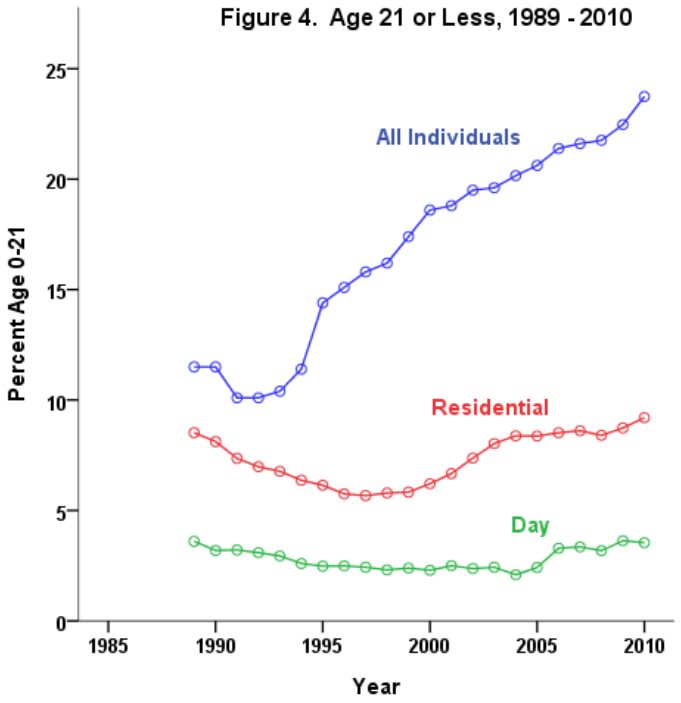
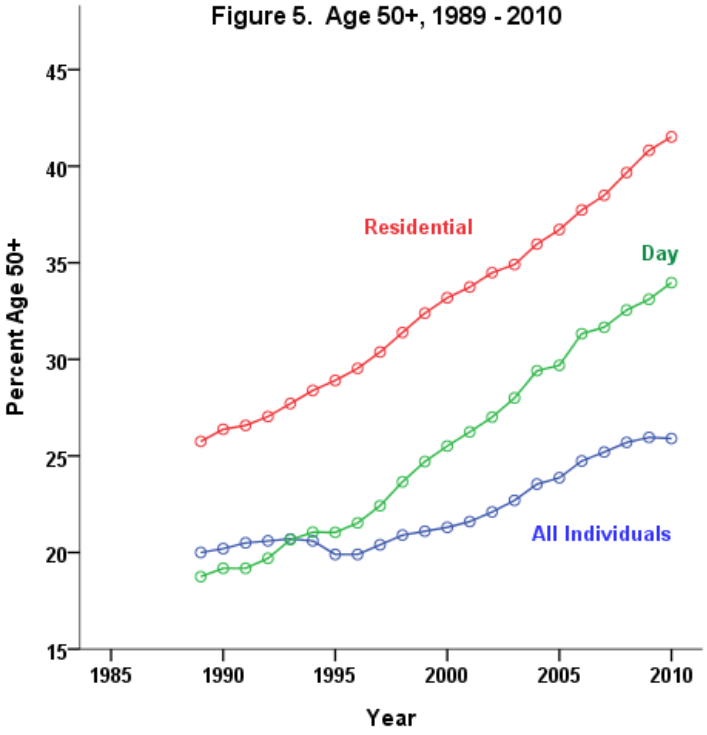
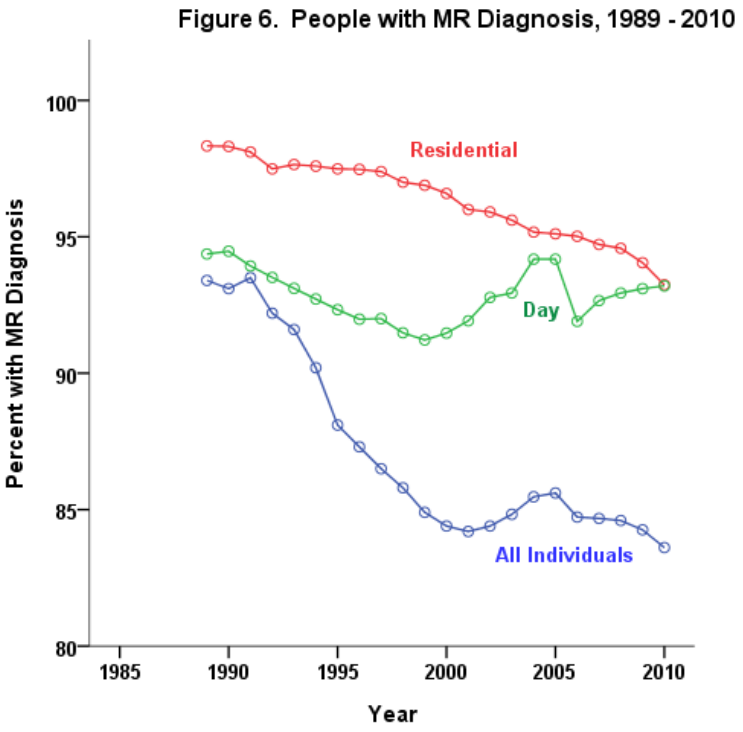


Figure 4 clarifies why mean age is not increasing for the *All Individuals* category: the increasing proportion of younger people among all individuals served is off-setting the aging of the overall service population. As the graph shows, young people are still relatively rare in both residential and day settings. Fewer than one in ten of the people living in OPWDD-certified residences are under age 22, a level that has varied somewhat over the years but has not trended. Since the vast majority of young people are principally served by the educational system, individuals under age 22 are even less common in the day services sector.



Among all individuals served however, the number of young people receiving OPWDD supports has been steadily increasing for years, to the point that now close to a quarter are under 22 years of age. This trend has profound implications for OPWDD and reflects the need for and growing importance of: family support, at-home supports, transportation, clinic services, employment, and related ancillary services.

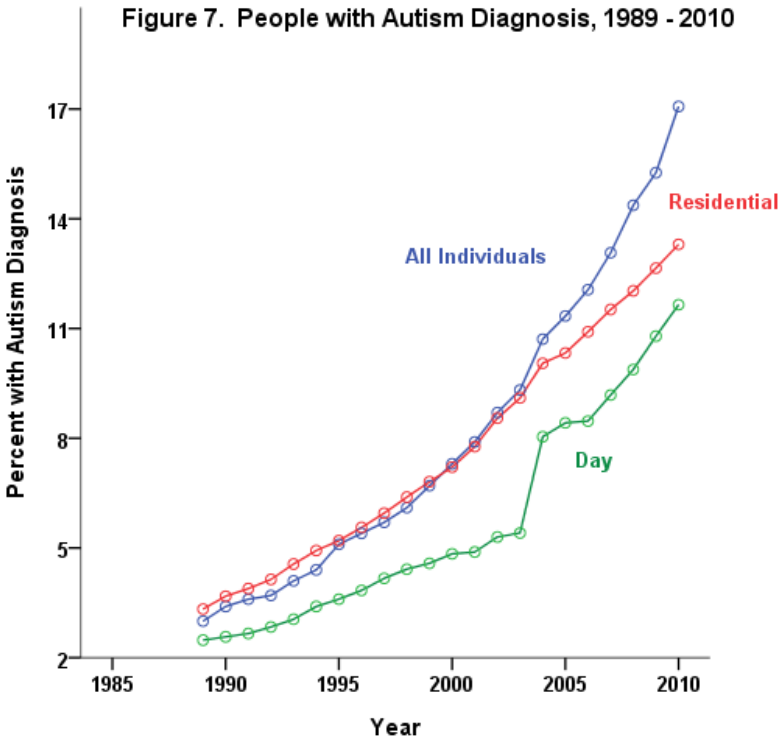
Finally, as Figure 5 demonstrates, the growing presence of older people among those served by OPWDD is a clear trend in all three groups: all individuals, out-of-home residents and day participants. However, the pace of the increase is especially notable in residential and day settings, mirroring the increases in mean age seen earlier. Among people living in residential settings, more than 40% are now 50 years of age



or older, and the upward 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 is actually 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.

As noted in prior Plans, the people supported by OPWDD are, at once, becoming younger and older, depending on the particular segment of OPWDD services. In residential settings, the average age is increasing at a pace where the average resident will be 50 within the next 20 years. At the same time, the rapid expansion of programs to support individuals at home with their families has led to younger individuals receiving services, keeping the average age of all individuals served relatively stable.

Another aspect of the overall population supported by OPWDD is diagnostic diversity, which is also increasing. For example, a clinical diagnosis of mental retardation (MR/ID) was once a universal factor among people served by OPWDD. Figure 6 shows that while intellectual disability is still widespread among residential participants, the prevalence among the individuals OPWDD serves 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 the clinical diagnosis of mental retardation among all individuals served, with the percent of people so diagnosed dropping from nearly 95% in 1989 to around 83% in 2010. This trend reflects OPWDD's focus on serving individuals with the full range of developmental



disabilities.

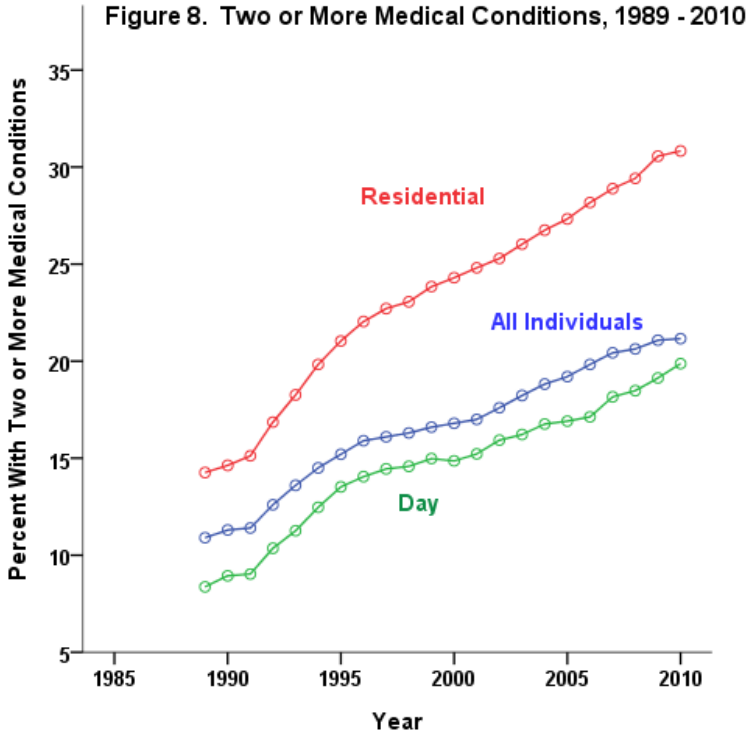
OPWDD has recognized and responded to the significant increase over the last two decades in the diagnosis of Autism/Autism Spectrum Disorder, illustrated by Figure 7. Among all individuals served, the percentage of people with an autism diagnosis has increased by more than 400%, from about 3% in 1989 to more than 17% in 2010.

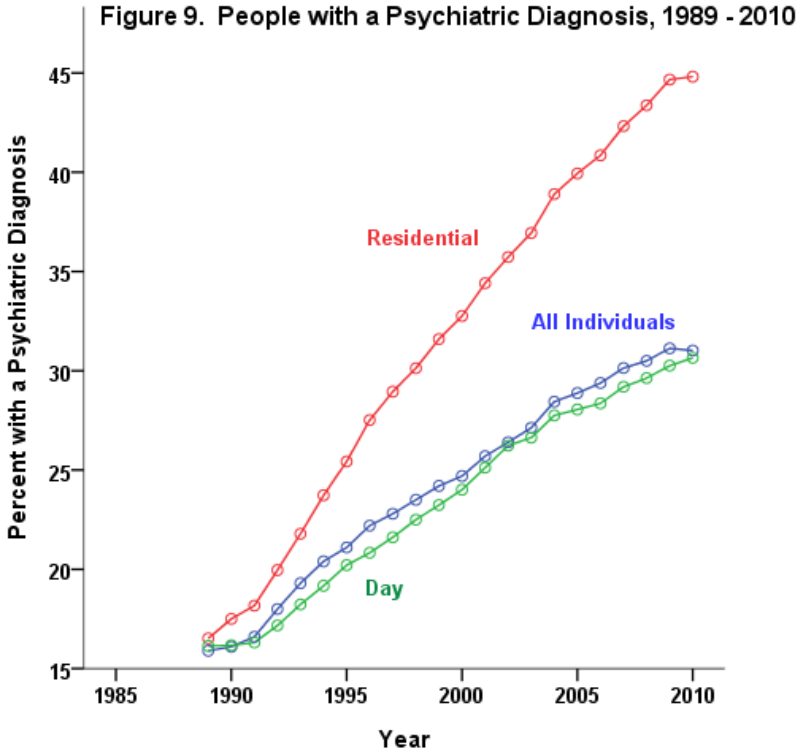
As shown in Figure 7, the *All Individuals* group emerged as the leading edge of autism growth, increasingly eclipsing those in the residential sector. This suggests the trend may be driven by higher rates among people living at home, a contention supported by much higher diagnostic rates among younger age groups served by OPWDD. The trend may also be accelerating, meaning that much higher rates of ASD diagnosis may still lie ahead.

People served by OPWDD also experience other disabilities secondary to their developmental disability. These diagnoses often drive the need for resources as much as, or more, than any developmental challenges. The next two figures highlight individuals with multiple medical conditions and dual diagnosis.

Figure 8 shows 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 other than the family home. In 1989, fewer than 15% of people living in an OPWDD funded residence were, by this measure, medically complex. By 2009, that proportion exceeded 30%.

Although both the *All Individuals* group and the day participants also show clear signs of increasing medical complexity, they continue to do so at much lower levels and at slower rates. Surely, both





the Home and Community Based Services (HCBS) Medicaid waiver and the Care-at-Home waiver for children with developmental disabilities and complex medical needs have enabled families to successfully maintain their family member at home.

Figure 9 shows another defining OPWDD issue of the last twenty years—the level of dual (developmental and psychiatric) diagnoses among people served. 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 nearly 45% by March 2010—an increase of nearly 150%. The trend in the other two groups is slower, but still significant.

In sum, OPWDD continues to support a complex and changing group of people. The overall service population is becoming, at once, younger and older; the expansion of programs to support families has led to more young people being served so that the mean age of all individuals has been fairly stable over the last two decades. This masks significant aging occurring among people living in OPWDD's core residential system who will need more age-related supports in future years.

The growth and reconfiguration of services

Four important trends have defined OPWDD's system of services and supports. First, a large institutional system has been dismantled, leaving only 1,434 individuals living in institutional settings as of April 2010, more than two-thirds of whom reside in special units designed to address serious behavioral challenges. Second, OPWDD and its not-for-profit provider partners have developed a vast array of supports and community-based services statewide. Third, responding to individual and family preferences, OPWDD has reduced the average size of the homes in its community residential system. Finally, OPWDD has utilized the HCBS waiver to vastly expand the types of supports it is able to offer as well as make services ever more responsive to the wishes of individuals. OPWDD is committed to continuing the transformation of its system of supports and services to be increasingly more person-centered, flexible, customized, and self-directed.

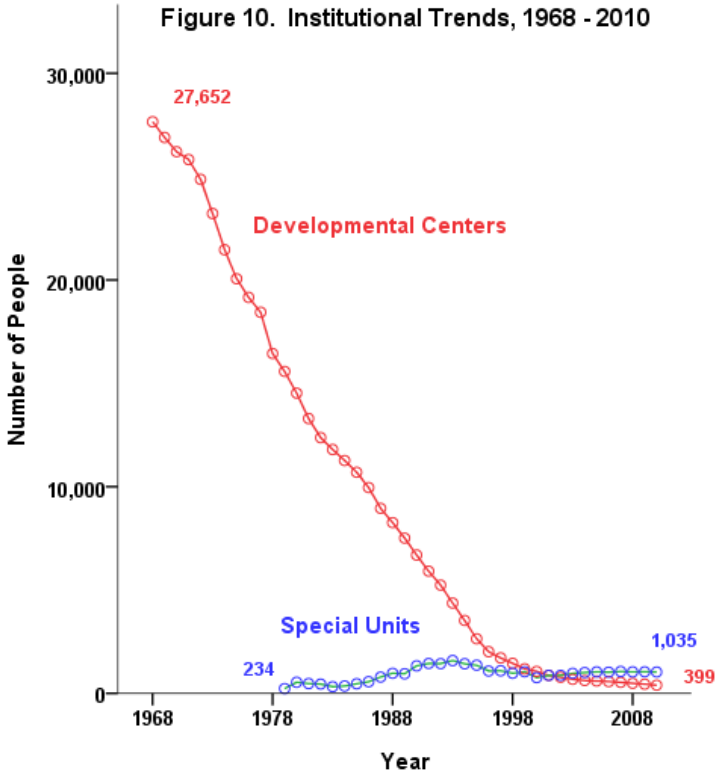
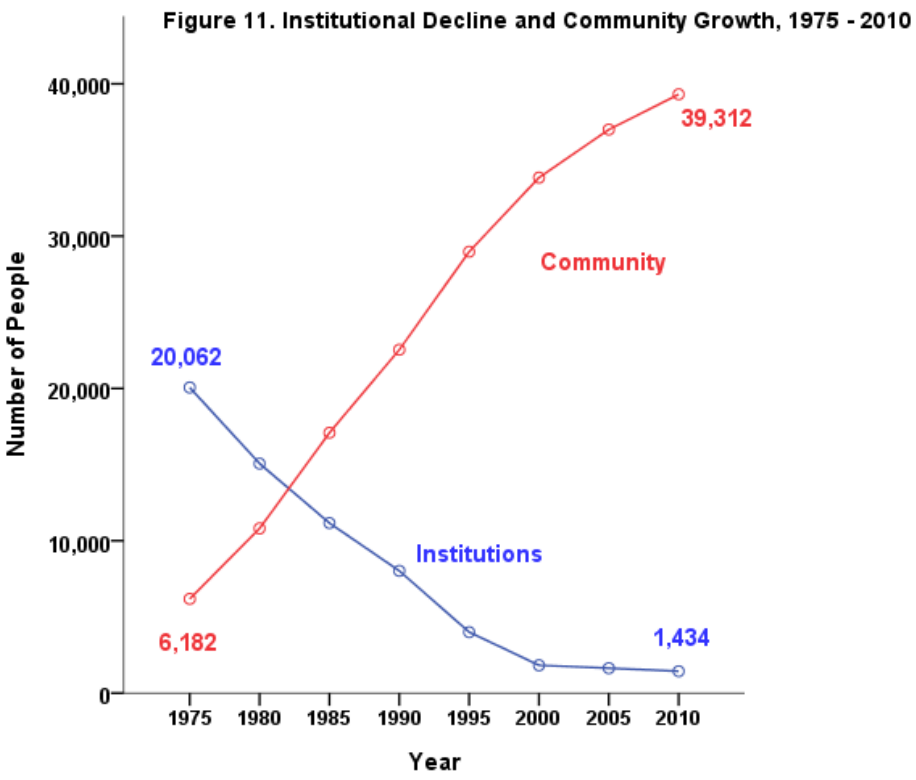


Figure 10 portrays OPWDD's hallmark achievement during the last four decades. Developmental Center (DC) enrollments declined from a peak of nearly 28,000 individuals in 1968 to a low of 399 by April 2010, a decrease of almost 99%. To meet the need for specialized environments and services of people with exceptionally challenging behaviors, special residential units have been established by OPWDD across the state, most on existing or former developmental center campuses. Figure 10 shows how, in

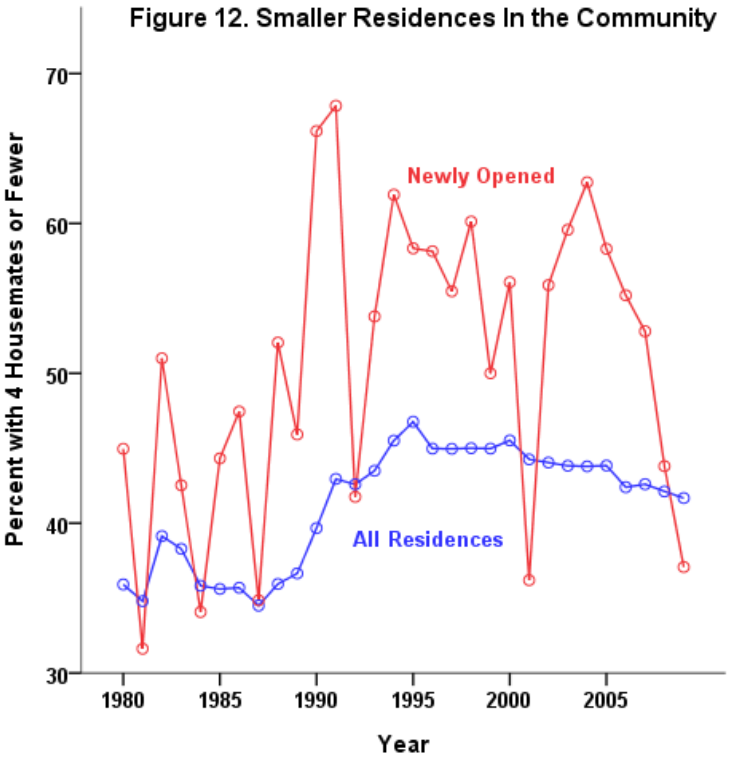
the midst of a dramatic decline in the number of general DC unit residents, the census of the special units has become relatively stable after an initial period of growth. Special units presently account for slightly more than 7 in 10 (72.2%) of the 1,434 people currently living in OPWDD's institutional settings.

As noted earlier, institutional decline tells only half of the story. The rest of the story is that this decline was accompanied by the creation of a large, statewide network of community living options, including community residences and individually controlled residential supports. Figure 11 illustrates the large increase in the number of individuals receiving residential services in the community. The number of individuals with developmental disabilities supported by OPWDD community residences, Consolidated Supports and Services (CSS), and Individualized Support Services (ISS) has grown over 500%, from 6,182 in 1975 to 39,312 by 2010. This development of residential opportunities for more than 30,000 individuals was significantly more than necessary to meet the demands of shrinking and closing institutions. These opportunities were created to address the desire of people with developmental disabilities and their families for a long-term living arrangement in and outside of the family home. OPWDD is committed to maintaining a full array of residential support options to meet the needs and wishes of individuals, their families and advocates and moving the system forward toward more creative options.



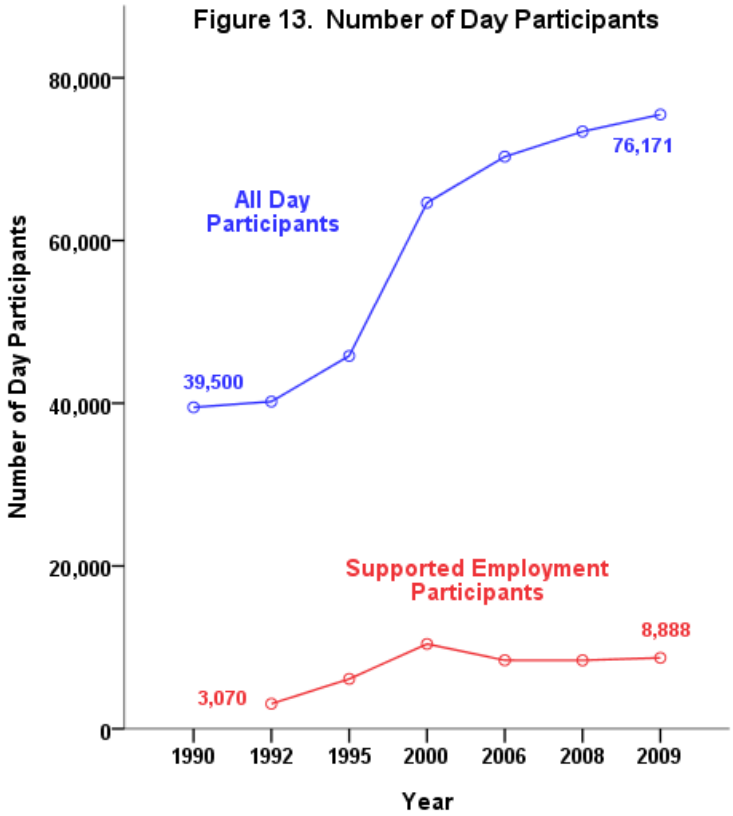
Concurrent with the downsizing of its developmental centers, the agency began reducing the size of community residential settings by reconfiguring existing programs and developing new, smaller residences. Figure 12 shows the percentage of residences designed for four people or fewer, a good indicator of the prevalence of smaller residences in the years from 1980 to 2009 (the most recent year for which a full year of data are available). Both community homes that are newly opened in a given year and all residences in operation that year are displayed.

The pattern in Figure 12 demonstrates variability in the percent of smaller homes developed since 1980, but the overall trend is clear and expected to continue. Many individuals and families have expressed a continued interest and desire for smaller homes; the development of smaller, more individualized options in uncertified settings will be discussed later in this Plan.

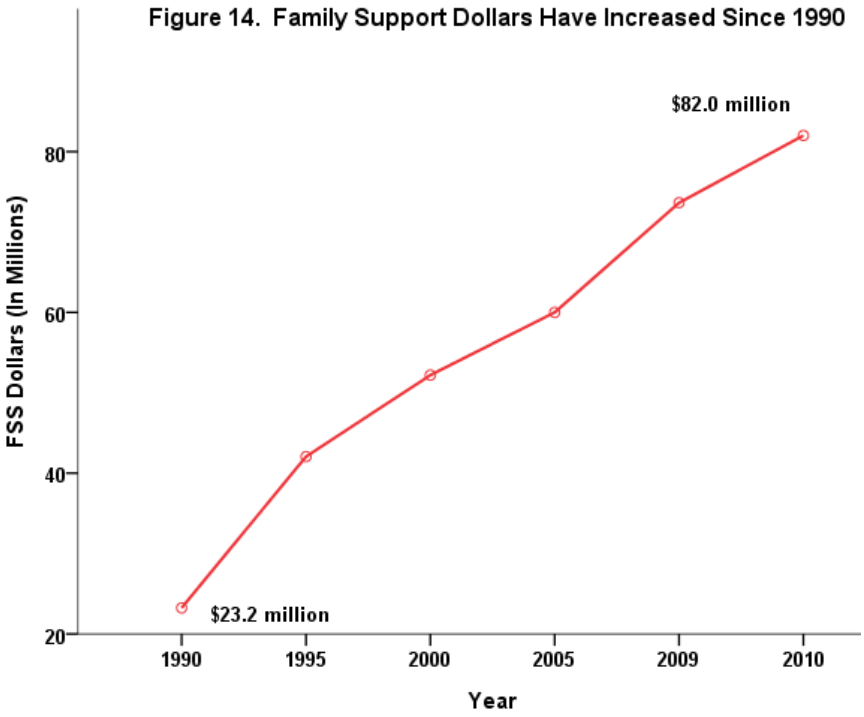


Accompanying the requests for smaller living situations is a desire for real participation in the community; a range of activities in the community and employment figure prominently on the list of outcomes desired by individuals receiving supports through OPWDD. In response, the opportunities for day supports and services have expanded in kind and number. The options range from comprehensive day treatment services to sheltered and supported employment, including activities for older people. There has been increasing desire for more opportunities for inclusive activities and involvement with one's community, including supported employment in a broad range of settings. Figure 13 shows the dramatic expansion of day activities to meet this demand. From 1990 through 2009, the total number of all day participants has increased by 89%. Behind these large and growing day enrollments there is a continuing reconfiguration of day options made possible by OPWDD's HCBS waiver. These changes have made more individualized opportunities available to greater numbers of people.

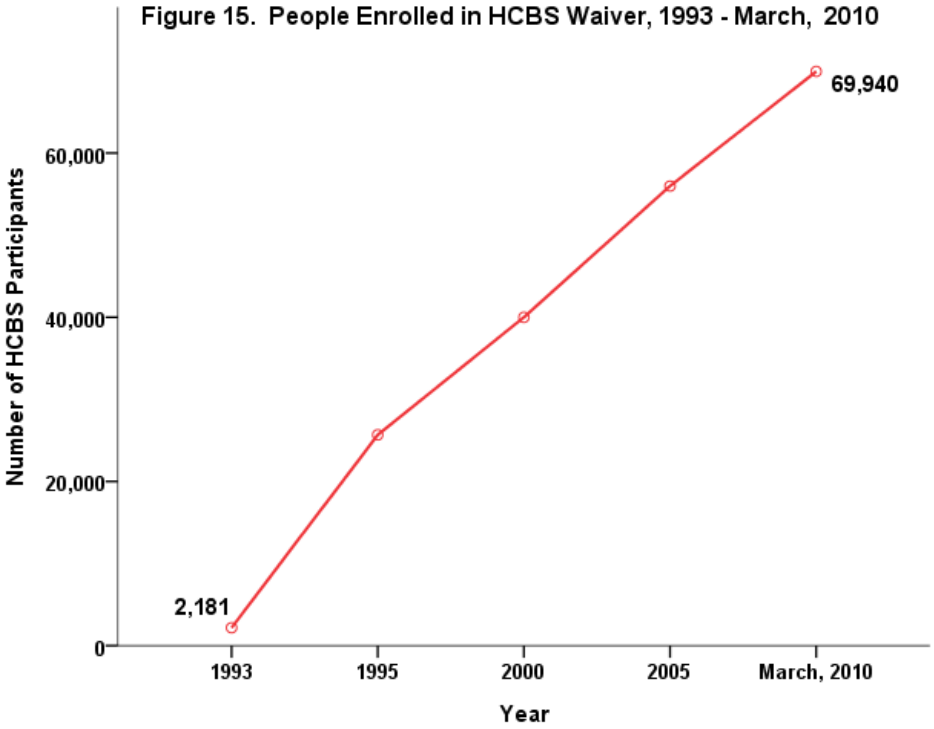
Figure 13 also highlights an increase in the number of people participating in OPWDD's supported employment services. This program experienced steady growth until about 2000, when an interagency agreement resulted in the transfer of supported employment participants who did not meet OPWDD's eligibility criteria to the NYS Education Department's (SED) Office of Vocational and Educational Services for Individuals with Disabilities (VESID) where they would be more appropriately supported. Since then, enrollments in Supported Employment stabilized at over 8,600. A renewed focus on employment outcomes and enhanced supports for individuals with significant challenges to successful employment has increased the overall number of participants to nearly 8,900. This number is expected to be buoyed by a new HCBS waiver service expressly focused on youth transitioning from high



school, and an overall emphasis on employment as a valued outcome for individuals. OPWDD currently supports 1,169 individuals in blended day services, which affords people the opportunity to participate in a combination of day habilitation, supported employment, and/or prevocational training, based on their needs and preferences. The success of blending day services has lead to the development of a distinct waiver service called *Pathway to Employment*, which will increase the number of individuals working. A more detailed description of employment initiatives is highlighted in Chapter 5.



In addition to an expanding range of community-based services and settings, OPWDD also provides a broad array of services for individuals living at home with their families. These supports include a variety of respite programs, recreation, counseling, parent/caregiver training, and more. Figure 14 shows that funding for this range of services, known as Family Support Services (FSS) has increased for many years, growing by more than 250%, from $23 million in 1990 to $82 million in 2010.



Implementation in 1991 of the HCBS waiver marked a new era for developmental disabilities services in NYS. The waiver offered the opportunity for increased flexibility in the design and delivery of supports and services, and was essential to OPWDD's continued transformation from an institutional system to a system dominated by high quality community-based services. The waiver provided the framework that allowed individualized services, person-centered planning, and the self-directed service options that

continue to be developed and refined today.

Figure 15 describes the growth of the HCBS waiver. Beginning in 1993 with the enrollment of 2,181 individuals, the waiver had grown to 69,940 people by March 2010. This represents an expansion of nearly 68,000 people in the last 17 years.

Chapter 3: Person First – Person-Centered and Self-Directed Supports

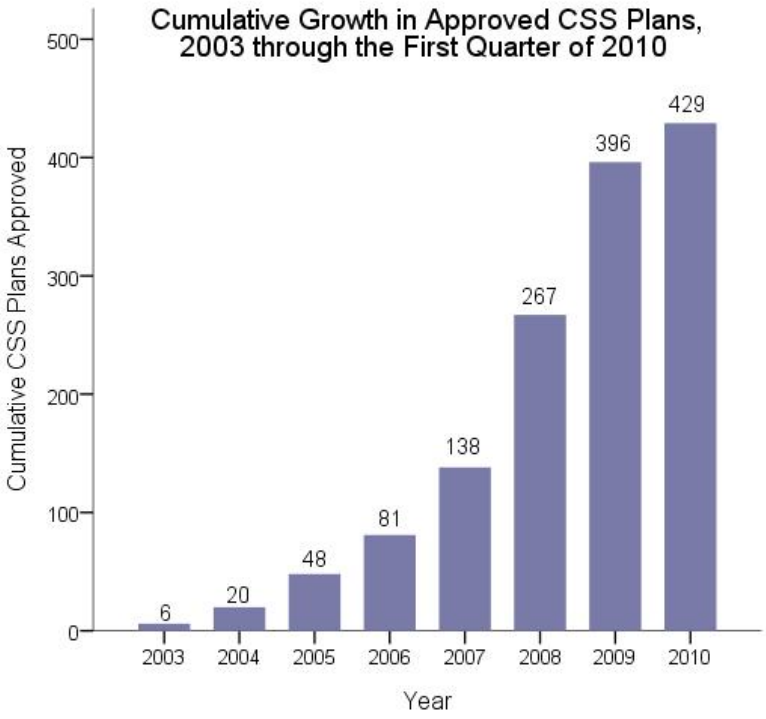
Over the past 40 years, the service delivery system for individuals with developmental disabilities evolved from a medical model with professionals in charge of treatment to a system that puts individuals and family members in control of planning and developing their services and supports. Incremental changes to the locus of control in the system have culminated in service options that are both person-centered and self-directed.

Person-centered means that the individual with developmental disabilities is the starting and ending point for all discussion and planning. Self-direction refers to supports and services chosen, designed and managed by individuals and those who support them; family, friends, advocates and staff, both paid and unpaid. One form of self-direction is known as self-determination and is distinguished from traditional service planning and delivery by three distinct factors: 1) individualized budgeting, 2) portability of the individualized budget and 3) self-management of staff (hiring, training, etc.).

Since 1998 OPWDD has implemented self-directed options, first through the Self-Determination Pilot Project, then Consolidated Supports and Services (CSS) and, most recently, through the Portal initiative. Through these initiatives, OPWDD has learned a great deal about helping individuals to achieve the lives they want and anticipates expanding these opportunities well into the future.

Consolidated Supports and Services

Initially developed as a funding mechanism for self-determination, CSS became a distinct service within OPWDD's HCBS waiver with renewal of the waiver in 2004. Its status as a waiver service has enabled increased numbers of individuals to determine and self-direct their supports and services. The Self-Determination Pilot Project was initially funded for a limited number of individuals. Once established as a HCBS waiver service, CSS quickly became a popular option for individuals seeking greater control over their lives. As shown in the accompanying graph, CSS has expanded to 429 active plans as of the first quarter in 2010.



CSS participants work with a start-up broker and their circle of support to develop a person-centered plan that highlights their strengths, support needs and goals for the future. An individualized budget is developed with each participant based on a Personal Resource Account (PRA), a target value that projects the annual cost of supports the individual needs and wants. Financial Management Services (FMS) are available through an entity that acts as the agency of record to assist with billing and other paperwork. With these supports in place, participants across the state have been able to pursue outcomes related to independent living, education and competitive employment. Many CSS participants express satisfaction with self-directing their own services and are quick to point out that the benefits of greater independence and authority also come with increased responsibility.

In addition to the positive outcomes for individuals and families, self-directed services like CSS produce fiscal savings. When compared to the estimated cost of supports and services for these individuals in traditional settings, CSS saved NYS approximately $3,560,274 this year alone. OPWDD is committed to further streamlining the CSS application and approval process to further improve access to self-directed services.

The Portal

In 2009, OPWDD began evaluating the accomplishments and challenges associated with self-direction. Although the agency found success with CSS, the next step was to develop a strategy to "balance the portfolio" of services and expand self-directed options to a greater number of individuals. This next phase of development is the new Portal initiative.

The Portal offers a fresh approach to service delivery, with an emphasis on flexibility, timeliness and fiscal integrity. Each of OPWDD's regional Developmental Disabilities Services Offices (DDSOs) was given an allocation to support approximately 10 individuals in designing and implementing a life plan (see Appendix D for state map of service regions). The Portal borrowed best practices from CSS such as person-centered planning, individualized budgeting, brokerage, portability, and FMS, with a focus on streamlining the planning and service design process. Currently, there are 121 active Portal participants across the state with the average budget at 74% of the PRA target value. Approximately half of the life plans include at least one staff person who was hired by the individual or their advocate.

The Portal improved the "customer" experience in accessing services and supports and also enhanced OPWDD's strategic direction toward building an infrastructure for individualized and self-directed services by:

- Revising the approach to reimburse housing costs for people living in their own homes.
- Significantly increasing the number of approved FMS agencies.
- Transitioning to hourly billing for individualized budgets, removing the need for labor intensive cash reconciliation on an annual basis.
- Revitalizing the ISP and service agreement instead of maintaining multiple habilitation plans.
- Broadening the scope of individualized planning and budgeting at the DDSOs.
- Simplifying the rate setting methodology that will be used for all individualized budgets, replacing distinct Portal and CSS budgets.
- Creating standard rates and service definitions for FMS and Service Brokerage.
- Improving collaboration between OPWDD and providers.

These steps will assist OPWDD to expand self-directed and individualized services as the agency moves forward.

In the future, OPWDD plans to integrate the fundamental components of CSS with the streamlined business practices of the Portal when developing new services. The current fiscal climate may not just be a challenge, but an opportunity to transform the system into one that is increasingly person-centered and based on individual choice.

Systems Transformation

The Real Choice Grant

In 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 "Systems Transformation" grants program under the "Real Choice Systems Change Grants for Community Living." The five-year funding award, totaling $2.86 million, is helping to transform OPWDD's service system into one that is more individualized and person-driven, enabling individuals to live in homes of their choosing and participate fully in community life.

Specifically, OPWDD is using three subcommittees (Choice, Funding and Housing) to advance three distinct but related goal 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 OPWDD's service system. The grant has become a major vehicle for moving much of the work related to system change forward. Specific goals identified in the strategic plan for the grant include:

Choice

- Increase the number, capacity and efficiency of new and existing organizations, including OPWDD, that deliver and foster individualized services across the life span.
- 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 ensure emphasis on individualized outcomes and quality of life indicators.
- Make understandable information about state and voluntary providers and the quality of services/supports available to all interested parties in accessible formats.

Funding

- Influence the ongoing cultural evolution within the OPWDD system 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.
- Develop new and improve existing collaborative relationships between OPWDD and other agencies to integrate processes and better meet the needs of people of all ages.

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 an 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.

The Transformation Advisory Committee

The Transformation Advisory Committee (TAC) associated with the Commissioner's Advisory Council was formed in July 2009 to track transformational change within OPWDD and across the service system, and advise the Commissioner on key transformational initiatives. This oversight body is ensuring that 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.

Now at the beginning of the fifth year of the five-year grant cycle, the Real Choice Systems Transformation grant continues to serve as the centerpiece of OPWDD's transformation agenda. The work completed thus far reflects the path that OPWDD and its provider network have taken to keep pace with customer demand for richer lives based on a home of one's choice, productivity, meaningful relationships and good health. At the conclusion of the grant in the Fall of 2011, the collective outcomes contained in the grant's final report will serve as a capstone for organizational change as well as a blueprint for further mileposts along OPWDD's evolving transformation.

Chapter 4: People live in a home of their choice

NYS-CARES

Launched in 1998, NYS-CARES is OPWDD's nationally recognized multi-year initiative to meet the out-of-home residential needs of individuals with developmental disabilities. In the time since its inception through March 31, 2011, NYS-CARES will have provided approximately 18,500 new residential opportunities for individuals with developmental disabilities. NYS-CARES encompasses living opportunities for individuals in newly developed homes as well as funded vacancies in existing homes. Currently, the NYS-CARES initiative emphasizes the development of creative residential options, such as supportive residences and other settings chosen by individuals and their families which do not require 24-hour supervision. This response to the expressed wishes of individuals and their families is balanced with the effort to ensure that the need for 24/7 supervised residential opportunities is also met.

Each DDSO has been provided a multi-year development allocation that combines residential habilitation and employment funding. The allocations were combined to allow maximum flexibility for the districts to meet individual needs while providing them with performance goals for both out of home residential and employment opportunities.

Although the allocations are substantial for these difficult fiscal times, they do not fully address the known demand for residential supports and services. OPWDD must work with its not-for-profit providers, and with individuals and their families, to ensure that the residential supports and services being developed are responsive to their desires and needs, that they champion choice and self-direction, and that they achieve these goals in a fiscally responsible way.

Home of Your Own

In the past year, OPWDD used its certification as a Department of Housing and Urban Development (HUD) approved Housing Counseling Agency to tailor projects to the needs of stakeholders. Existing projects were expanded and new ones were created to assist people with developmental disabilities, their families and the workforce to save for a home, purchase their first home, rent or lease an apartment, repair credit, avoid foreclosure, and maintain their existing home.

Funding from HUD to OPWDD, totaling $165,000, made possible both new and existing projects. Grant funds not only allowed for the expansion and creation of projects, but also enabled OPWDD to provide outreach, orientation sessions, housing counseling, training and technical assistance, homebuyer education and other services to more than 4,000 people, including those with developmental disabilities, their family members, the workforce, and a network of partners.

The Home of Your Own (HOYO) and HOME Grant programs are the longest tenured independent housing programs at OPWDD. HOYO was established in 1996 and is open to income-eligible people with developmental disabilities and/or mental illness, and their parents or legal guardians. The program offers a wide range of supports to homebuyers and, through partnership with OPWDD, the Housing Finance Agency (HFA)/State of New York Mortgage Agency (SONYMA) makes available a 4 percent, 30 or 40-year fixed mortgage to eligible participants. Participants must be first-time homebuyers and may apply along with co-borrowers, friends, parents, or legal guardians who are not disabled. However, the person with a developmental disability must live in the home acquired through HOYO. As of winter 2009, HFA/SONYMA funded 235 mortgages, totaling $19.8 million.

In the late 1990s, OPWDD applied for and received its first HOME Grant. The grant is administered by a local not-for-profit agency in the Capital District and is operated by OPWDD. The purpose of the HOME program is to assist first-time homebuyers with developmental disabilities and their parents or legal guardians with down payment, closing costs and minor repairs. The Home grant is available in seventeen NYS counties.

Some of the other housing projects implemented by OPWDD include:

- Assets for Independence/Individual Development Accounts: This program assists participants to achieve the goal of purchasing their first home through the use of a matched-savings program; for every $1 the individual saves, OPWDD will match it with $4. A total of 360 accounts will be set up in six DDSO regions across the state.

- Preventing Foreclosures: Now more than ever, there is a need for trained and certified foreclosure prevention counselors. OPWDD established a foreclosure prevention unit to assist homeowners with keeping their homes, with counselors certified in foreclosure basics.

- Section 8 Rental Assistance Vouchers: OPWDD has partnered with the New York City Housing Authority (NYCHA) to offer rental assistance vouchers to income-eligible families in the downstate area.

- Credit Counseling: All HOYO participants must have an average credit score of 620. Applicants that fall short of this score are counseled by OPWDD staff on how to improve their score.

- Housing Office Newsletter and Blog: To keep individuals and providers up to date on OPWDD housing initiatives, a quarterly newsletter was developed. All issues will be distributed throughout OPWDD, NYS and nationally to private and public partners. In the near future, a blog will be developed to provide up to the minute news and information pertaining to OPWDD's independent housing activities.

Family Care

OPWDD's Family Care program remains focused on the provision of choice to individuals who seek fulfillment through opportunities that reflect their personal goals. Supporting the specific needs of individuals requires the cooperative effort of those dedicated to the unique nature of Family Care, particularly the Family Care providers who open their homes to individuals with developmental disabilities who would like to live in a family setting.

Family Care is poised for a systemic change as new ideas are used to further invigorate this program. Currently, the program supports slightly more than 2,500 individuals in nearly 1,400 homes statewide. Over the next several years, OPWDD plans to support individuals through the expansion of Family Care within the voluntary sector. The intent is to provide more flexibility and availability of supports to more people seeking the benefits of living in a family home.

Each DDSO in cooperation with other stakeholders, including local provider agencies, advocates and the Statewide Family Care Advisory Council, will play an integral part in the development, promotion and implementation of the new approach. By building on the sound basis of the current program, a more dynamic and efficient Family Care program will offer broader options for individuals and their families.

Family Support Services

Core to OPWDD's commitment to Putting People First is supporting individuals and families who wish to stay together as a unit to do so. In addition to supporting an irreplaceably nurturing family environment for the individual, supporting families to stay together is also cost-effective. Family Support Services (FSS) can be instrumental in avoiding a premature and unwanted move to an out-of home setting.

Since its inception in 1984 as a legislative demonstration project, FSS has grown from a program serving some 200 families to an array of services supporting more than 43,000 individuals and their families. The services

include information and referral, family and individual counseling, after-school programs, transportation, and respite. Many families indicate that respite is one of the most valuable supports they receive.

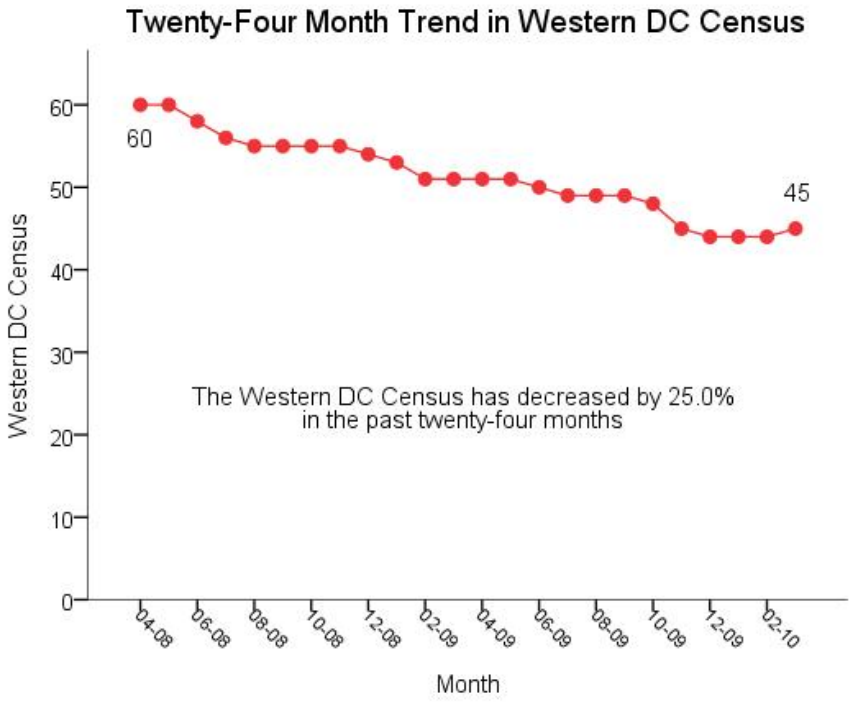
In the 2010-11 budget, funding for FSS has been expanded by $7 million dollars to serve the ever increasing need, thus enabling individuals to remain at home and receive nearly 73,000 individualized services.

Redefining Institutional Services

OPWDD's enacted budget for 2010-11 allows the continued development of community living opportunities for individuals in institutional settings. This will enable OPWDD to further downsize and redefine its institutional capacity, which comprises a small developmental center capacity at several sites and a number of small specialized units to meet the unique needs of the people residing there.

As the first step in a revitalized multi-year plan to downsize and eventually close developmental centers, two years ago OPWDD initiated the transition of the majority of individuals residing in the Western NY Developmental Center to community living situations (see graphic below). This transition is progressing smoothly and projected to conclude in 2011, affording the 45 people still residing there the opportunity to live in the community. The rundown and closure of the remaining developmental centers, where fewer than 400 individuals currently live, is also underway. This will be accomplished via a combination of state and not-for-profit agency development over the next several fiscal years and a halt to new developmental center admissions.

While closures will continue, it is expected that there will continue to be a need to provide services to a limited number of individuals in more structured settings until they can be supported appropriately in the community. OPWDD is therefore committed to maintaining quality services in those settings in order to maximize opportunities for the development of the skills needed to make a successful transition to community living. The aim of short-term intensive services is to enable individuals to build successful lives in the community - the heart of redefining OPWDD's institutional capacity.



Person-centered planning for people leaving institutional settings must address all needed supports and services in the community, identify potential providers and delineate responsible parties for implementation of the plan. Through the Community Placement Process (CPP), initiated in September 2007, approximately 215

individuals have transitioned from an institutional setting (including nursing homes) to a community setting. In redefining institutional capacity in this way, OPWDD also remains committed to the employees who have been supporting the residents. Seeking to fulfill this commitment and support the continuity of relationships developed between individuals and staff, the development of residential opportunities for downsizing will provide opportunities for both the state and not-for-profit workforces.

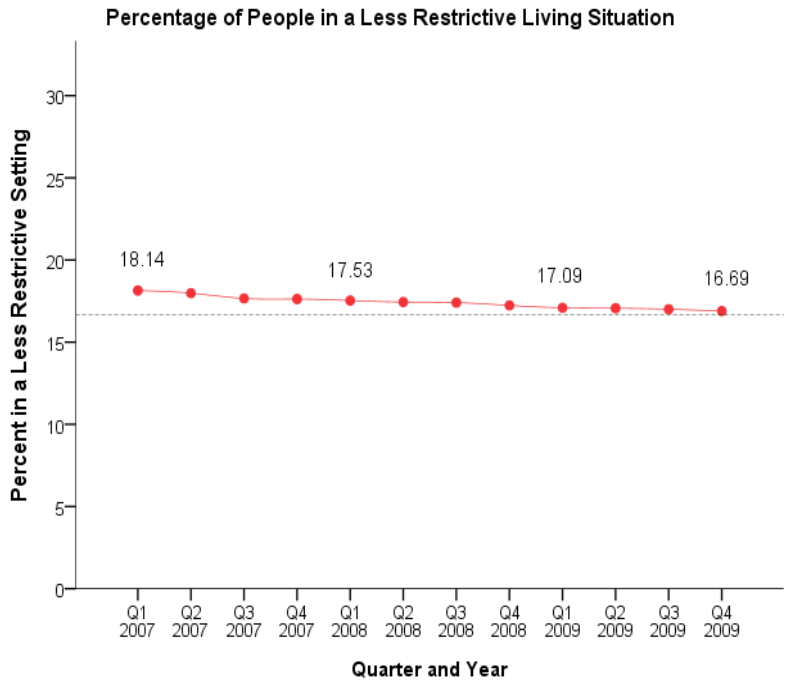
Performance measures:

As part of monitoring progress toward supporting people to live in homes that do not require 24-hour supervision, OPWDD has committed to tracking the number of people who are living in less restrictive settings over time. Metric 1 includes living situations where OPWDD funds the physical residence where the person lives. People living in Supportive Individualized Residential Alternatives (IRAs), Supportive Community Residences (CRs), Family Care, and Individualized Support Services (ISS) (rent subsidies to maintain an independent living situation) are all considered to be living in less restrictive settings. This metric targets an important goal of our service system – to empower people to live more independently. Concurrently, the extent to which people have choice and satisfaction in their living arrangements will also be tracked over time. Periodically, we will examine whether people in less restrictive settings are more satisfied with their living arrangement compared to individuals in other settings. To summarize, OPWDD will track:

1. Systemic movement toward residential settings that are less restrictive.
2. Satisfaction with and choice over living arrangements.

The trend for the first metric can be found below. Longitudinal data are not yet available for the second metric.

Metric 1.



From 2007-2008 the percentage of people who are living in a less restrictive setting fell slightly each quarter and has leveled off in 2009 to 6,823 individuals. This trend is partially influenced by (1) the decrease in the number of people living in Family Care, (2) the limited amount of new program development because of the fiscal environment and (3) the 27% increase in the number of people receiving at-home residential habilitation from 7,824 to 10,681 in three years. Therefore, more individuals are choosing to live and receive support in their family home or in their own home, which is not reflected by the numbers in Metric 1. Future metrics will focus on shifts to less restrictive settings in new residential development.

Chapter 5: People work and fully participate in their communities

Employment First

OPWDD is promoting *Employment First* as a preferred outcome for all people with developmental disabilities. Employment helps individuals achieve the personal, social and monetary benefits that all working people enjoy. By earning a paycheck, people experience the financial freedom to participate in activities of their own choosing and become more fully engaged in their communities. The objective of *Employment First* is to increase the number of individuals with developmental disabilities who are working in their local communities.

For those people who are not working, *Employment First* stresses an individualized approach to community contribution through volunteerism that not only "gives back" to a worthy cause, but also develops those skills and capacities that could potentially create a path toward employment.

OPWDD has undertaken several initiatives designed to assist people with developmental disabilities to work and participate in community life, so that workplaces and neighborhoods truly reflect all of New York's citizens. In 2009/2010, DDSOs were given a funding allocation to expand employment outcomes in their districts. The allocation gives the DDSOs flexibility in using the funds while requiring them to meet certain employment goals.

The *Employment First Platform* was drafted in 2010 and sets forth OPWDD's values and vision about work and community contribution. *Employment First* catalogues the proposed action steps to increase work opportunities for people with developmental disabilities. The *Employment First Platform* draft was widely distributed to stakeholders for comment and many opportunities were provided for interactive discussion and feedback. The *Employment First Platform* will be finalized during the Fall of 2010.

Enhanced Supported Employment

In 2009 OPWDD launched *Enhanced Supported Employment*, a pilot to assist individuals to achieve their employment goals. The pilot will support at least 700 new people in employment over a five year period. This pilot is designed to promote OPWDD's *Employment First* agenda and will serve as the basis for assessing new and creative approaches that can assist people with developmental disabilities to achieve their goals. One such approach is the agreement OPWDD entered into with the Department of Labor so that businesses that hire people through the *Enhanced Supported Employment* pilots can take advantage of federal tax credits under the Work Opportunity Tax Credits (WOTC) program.

Information provided by the *Enhanced Supported Employment* pilot evaluation will assist OPWDD to assess the effectiveness of the pilot and develop future policy. In particular, OPWDD included transportation to work as a possible service because transportation is often cited as a major barrier to employment. OPWDD will evaluate how transportation services are used to enable individuals to work. During the first half of 2010, despite a poor economy and high unemployment rate, more than 200 people successfully secured employment as result of participating in *Enhanced Supported Employment*.

Social Security Work Incentives

During 2009, OPWDD provided training on Social Security work incentives to all of the employment pilot projects. The training included information to dispel myths about the negative impact of employment on public benefits and entitlements. OPWDD has encouraged all interested stakeholders to participate in the

training on Social Security work incentives provided by Cornell University through the *NY Makes Work Pay Medicaid Infrastructure Grant*.

Ticket to Work

In January 2010, CMS issued a clarification letter to state Medicaid Directors advising that there is no conflict inherent in agencies receiving Ticket to Work funding for employment outcomes as well as HCBS funding for supported employment services. This paved the way for a videoconference, conducted by OPWDD in partnership with Cornell University, on the financial benefits to providers of becoming an Employment Network through the Ticket to Work program. As a result, nine agencies have become or are in the process of becoming an Employment Network.

Staff Training

To ensure that individuals with developmental disabilities have the best possible employment outcomes, support staff need adequate supported employment training. During 2009/10, OPWDD was able to provide introductory training for new employment programs and service coordinators on strategies for accessing employment services. More training is planned for stakeholders during 2010/11 that will frame the *Employment First* vision and share practices for implementation in local communities. In collaboration with state and voluntary partners, OPWDD will continue to coordinate training for employment support staff.

Employment Training Internship Program

In an effort to provide expanded opportunities that lead to long-term employment in the private, public and not-for-profit sectors, OPWDD implemented the Employment Training Internship Program (ETP). ETP enables businesses to employ individuals with developmental disabilities and have their wages paid by OPWDD for up to 18 months. As of 2010, the program has grown to include 300 interns. ETP also partners with local school districts to enable more than 200 high school students to gain work experience while still in the public education system. ETP staff assist these students with life planning to ensure a smooth transition from school to work. ETP is available to individuals across the state through programs at every DDSO.

Students Work Too

To support the dreams of many young people with developmental disabilities who want to transition from high school to employment, OPWDD is developing a strategy to assist high school students to secure after school jobs during the last two years of high school. This service will support young people to earn money by enabling them to work after the school day and during school vacations, with the support of a job coach. Specifically designed to occur after school hours, this service will be coordinated with mandated transition planning and students will be referred to VESID for post-high school vocational planning in the second semester of high school.

Works for Me

A major strategy for promoting individuals participating in the developmental disabilities system as a workforce is the employer recognition event, *Works for Me*. Each October, employers are honored for their commitment to workforce diversity by hiring qualified individuals with developmental disabilities. In addition to honoring employers, OPWDD celebrates the partnership between employer and valued employees, resulting in a truly unique event.

OPWDD is also developing a web portal for employers who are interested in hiring people with developmental disabilities. The portal is expected to launch in the fall of 2010 and will provide employers with an interactive link to local employment agencies in their communities.

Pathway to Employment

A new service was included in the OPWDD HCBS waiver renewal that will assist individuals enrolled in day habilitation programs to become competitively employed in their communities. The new service, currently in the design phase, is tentatively called *Pathway to Employment. Pathway* will assist motivated individuals to become employed through a person-centered discovery process that results in the development of a vocational plan, consistent with each person's strengths and capacities. This new waiver service will provide individualized community experiences that result in employment.

Volunteerism

OPWDD is developing an employment and volunteering guide for use by the DDSOs. This overview will provide regulatory and service option information that can help guide the development of employment (including self-employment), career exploration and volunteerism for individuals. Sometimes a lack of clarity around regulation and policy inhibits creative solutions that could increase volunteerism and employment. This overview will provide DDSO staff with a better understanding of the pertinent regulations that apply to these activities.

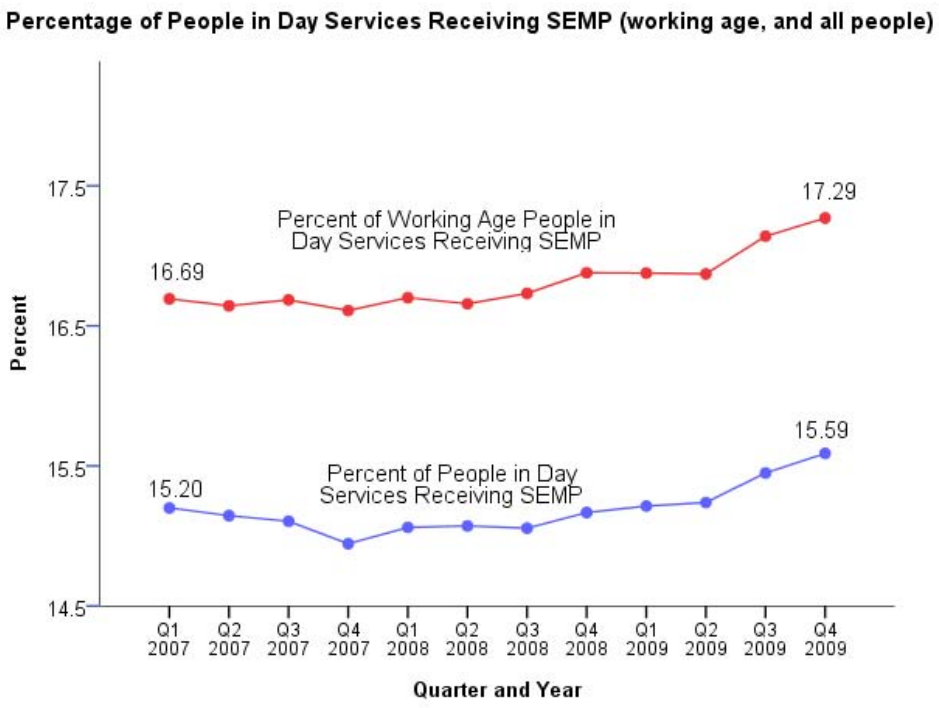
Performance measures

The overall objective of Employment First is to increase the number of people with developmental disabilities who are working in their local communities. OPWDD has developed indicators measuring the extent to which our service system supports individuals who choose to work. First, we will trend the percentage of people enrolled in day services who receive supported employment (SEMP). Potentially hundreds of individuals could be successful in a work setting with the proper level of supports, but for various reasons these individuals currently participate in other types of day activities. Acknowledging people's desire to earn income and ability to work, OPWDD is making good progress in creating opportunities for people who express interest in working, and we expect continued growth in services that support people in the workplace. Second, we will also trend indicators that provide feedback about whether we are meeting the demand for work opportunities. To summarize, OPWDD will track:

1. Systemic movement away from day activities and toward work activities.
2. Opportunities to earn income.
3. Demand for employment for those with no job and demand for more working hours for those who have a job.

The trend for systemic movement toward work activities follows. Reliable longitudinal data are not yet available for the second and third metrics.

Metric 2.



Trend lines for the percent of people in day services receiving SEMP are provided for people who are working age (23 through 64 [red]) and all individuals [blue]. One would expect the working age population to be more likely to show an increase in this trend. Increases in these trend lines indicate movement toward providing more opportunities to support people in the workplace.

Chapter 6: People enjoy meaningful relationships with friends, family and others in their lives

Community Habilitation

OPWDD supports community contribution that is individualized and reflective of each person's valued outcomes. With the goal of furthering individualization and community participation, OPWDD received approval from CMS to add a new service called Community Habilitation. Community Habilitation will subsume residential habilitation and offer greatly enhanced flexibility to meet individual needs and desires. To this end, OPWDD has developed a broad definition of the new service, which will be implemented in two phases.

The first phase of the Community Habilitation implementation process, targeted for November 2010, will transition the At Home Residential Habilitation (AHRH) service to the Community Habilitation model. During this implementation phase, Community Habilitation will be available for individuals enrolled in the HCBS waiver and residing in non-certified settings who choose to receive this service. The second phase, targeted for 2011, will address service availability for individuals residing in any waiver appropriate residential setting including certified settings (within parameters to be established.)

Community Habilitation is designed to be flexible and meet the needs of the individual so that the service can be provided seamlessly where needed, both at home and in the community. Community Habilitation supports

the individual's preferences for community participation, whether through volunteerism, community service or other individualized outcomes.

Everyday Heroes

OPWDD'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 efforts to 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 inclusion from a direct care perspective.

The Developmental Disabilities Planning Council (DDPC), the Civil Service Employees Association (CSEA) and Westchester ARC partnered with OPWDD to produce the *Everyday Heroes Instructional DVD* and *Users Guide*, which have been disseminated widely throughout NYS, the nation, and even internationally. The DDPC also funded 10 agencies to incorporate *Everyday Heroes* values within their organizations, implement best practices for inclusion by their direct support professionals, and then mentor other agencies to adopt *Everyday Heroes*.

OPWDD is now entering our 10th year of implementation and *Everyday Heroes* is now more than a training curriculum -- it is a culture that has been embraced by OPWDD and voluntary providers. *Everyday Heroes* is about direct support professionals throughout the OPWDD network of services who help people with disabilities make community connections everyday. These personnel are key to building community connections on behalf of people with developmental disabilities as they nurture relationships with community members and build alliances with families and advocates. It is interesting to observe the unique strategies for inclusion that come from the collective imagination of direct support professionals, administrators and clinicians -- how and why a person's life changed, and how a person moved from old ways, to better and ultimately best practices in community inclusion. *Everyday Heroes* demonstrates that the "ultimate best" is evidenced by the impact people with developmental disabilities, staff and community members make on their communities, working together. It is also about the organizations that embrace the *Everyday Heroes* values, where direct support professionals are celebrated for their dedication and desire to take on a leadership role and in doing so, to develop personally and professionally. *Everyday Heroes* organizations support a learning journey that includes commitment, discovery, imagination and change from traditional practices. Staff are recognized for their endurance and accomplishment in supporting people with developmental disabilities.

OPWDD convened regional video conferences during 2009 and 2010. These conferences have offered the opportunity to share stories and best practices, and have highlighted the importance of *Everyday Heroes*, as people who make a large and calculable difference in the lives of people with developmental disabilities. Future regional video conference events will provide "how to steps" for organizations looking to build an infrastructure that supports the *Everyday Heroes* values of direct support development and community connections. Stories will also be added to the OPWDD website under *Community Connections* to illustrate creative approaches to community membership that result in relationships and belonging for everyone.

Creating Connections

People with developmental disabilities need positive relationships with the people in their lives to the same degree as any one of us. Productive relationships with the people who support them as they plan their lives

and pursue their daily activities are essential to success and significantly affect the overall quality of life. Along with their family members, friends and other advocates, staff play a crucial role in the lives of people with developmental disabilities. The *Creating Connections* initiative was launched at the Capital District DDSO in 2008, in collaboration with the State University of New York at Albany School of Social Welfare, to strengthen the essential relationships between individuals and the staff that supports them. The initiative incorporates research and exemplary practices into a training curriculum for direct support professionals and clinicians to enhance relationships and thereby reduce abuse, neglect and other serious reportable incidents. Following this successful pilot and development of an "Assessment Toolkit" of exemplary practices, the "Toolkit" was disseminated to other regions of the state. It is being used to assess the organizational culture of each DDSO and instill a culture of quality that enhances relationships between individuals and staff.

Faith Based Initiative

The *Spirit Project*, a faith-based initiative funded by the DDPC, is in its third and final year of implementation. In collaboration with the Consortium on Innovative Practice and Central NY DDSO, approximately 50 individuals with developmental disabilities received assistance in exploring spirituality and participating in the congregation of their choice. Although the *Spirit Project* is scheduled to be completed before the end of 2010, OPWDD is committed to replicating exemplary practices from the project in other areas of the state. Three practical tools being integrated into the service delivery system are as follows:

1. **Spiritual Indicator Guide:** Medicaid Service Coordinators (MSCs), Active Treatment Coordinators (ATCs) and Qualified Mental Retardation Professionals (QMRPs) will use this assessment tool to evaluate the faith and spiritual interests of individuals with developmental disabilities. Two DDSOs have incorporated the guide for service planning and its content is available in a three hour course for MSCs, ATCs and QMRPs.

2. **DSP Training Manual:** The purpose of the training manual is to help Direct Support Professionals (DSPs) develop further in areas of empathy and compassion for individuals with developmental disabilities. The content in the manual emphasizes the importance of accessing places in the community (i.e. houses of worship, entertainment, sports and recreation) that lead to meaningful relationships with family, friends and other natural supports.

3. **Faith Community Inclusion Guide:** This inclusion guide provides practical strategies to help staff explore issues related to spirituality and engaging with faith communities.

In an effort to replicate the positive outcomes of the *Spirit Project* in Central NY, OPWDD initiated the *Faith Project* to support the spiritual needs of individuals with developmental disabilities in other parts of the state. Finger Lakes DDSO and Capital District DDSO are the first regions to participate. Both DDSOs are developing plans that utilize staff to help discover and assess faith/spiritual interests, connect people to their preferred faith community, and integrate outcomes into Individualized Service Plans (ISPs).

Performance measures

OPWDD recognizes that involvement in community activities is one step in helping people foster positive relationships. However, it is not enough that people have opportunities to participate in their communities - activities should be actively chosen by individuals, be meaningful to them and should provide a real

opportunity to connect to others with similar interests. Results from the National Core Indicators (NCI) project show that a majority of people who belong to a community group report making friends through participation in the group, but fewer than half of the individuals surveyed report belonging to a group (07-08, New York State Report). Measures of choice in community activities are in the process of being integrated into the 2010-2011 NCI Consumer Survey. Defining community choice measures and indicators that target whether individuals we serve have meaningful relationships is the starting point for metrics to monitor true community inclusion. To summarize, OPWDD will track:

1. The extent to which people experience choice in community activities.
2. Existence and quality of relationships.

Longitudinal data are not yet available for these metrics.

Chapter 7: People experience personal health and growth

Behavioral and Physical Health

The quality of every person's life is affected by his or her behavioral health. The principles of individualized services and person-centered planning must be applied when designing interventions to help individuals with developmental disabilities. This includes making behavioral changes that lead to personal growth, development and an improved overall quality of life. Therefore, intervention plans must be developed from the desires and needs that motivate each individual's behavior, based on observation and analysis. Staff need to be trained to recognize behavior as a means of communication, and to support people in positive, nurturing environments that ensure respect for individual rights and safety.

OPWDD provides workforce training in positive behavioral supports, and crisis management and intervention. In the future, OPWDD and service providers will 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 going through the final stages of transition to the new PROMOTE (Positive Relationships Offer More Opportunities To Everyone) curriculum. Drafts of the new training chapters were finalized and presented in a three-day workshop with Master Trainers. Clinical staff held videoconference sessions with the statewide workgroup to solicit review of additional and revised activities within the PROMOTE curriculum. Approximately two-thirds of the Level 1 curriculum has been reviewed. OPWDD Senior Management has been briefed on PROMOTE and funding will be allocated for producing educational materials for trainers and trainees.

Through the process of Functional Behavioral Assessment, a psychologist is able to investigate and communicate the processes underlying an individual's behavior and create effective strategies and supports to form a Behavior Support Plan. A four-part series of trainings on the comprehensive assessment and diagnostic evaluation of older individuals with intellectual and developmental disabilities was scheduled between April and September 2010. Three of the four training sessions have been delivered.

OPWDD has developed Communities of Practice for the clinical disciplines within the agency. Clinical personnel often find it challenging to meet the unique and complex clinical needs of individuals. To address this, multiple training programs for clinicians were developed that incorporate evidence-based practices and are presented by experts in their field. In Spring 2010, OPWDD offered a two-day training by an internationally recognized expert on providing treatment for individuals with developmental disabilities who are sex offenders living in least restrictive settings.

Intensive Behavioral Services

During the process of renewing the OPWDD HCBS waiver, a new service was added entitled Intensive Behavior (IB) Services. Implementation of this service was kicked off on July 1, 2010 across the state. IB Services is specifically aimed at addressing the needs of families caring for a child or adult at home who is displaying challenging behaviors that threaten the capacity of the family to cope and result in increased risk for out of home placement. This service comprises a high quality, time-limited, intensive intervention that includes functional behavioral assessment, the development of a targeted behavior management plan, extensive training by clinicians for parents and other caregivers in the home, and transition planning activities. The goal of the service is to provide families with the behavior management skills necessary to achieve and maintain community stabilization, and allow the individual's continued participation in community programs, routines and activities. OPWDD will be reviewing implementation progress of this new service and monitoring outcomes with providers of IB Services and service recipients during the first year pilot phase. Necessary modifications in the service design and/or delivery will occur as warranted.

Clinic Services

Clinics established under Article 16 of the Mental Hygiene Law continue to be one of the main vehicles by which OPWDD provides necessary long-term therapies to individuals with developmental disabilities. OPWDD manages and oversees the detailed review and approval process for new Article 16 clinic programs, and is responsible for the implementation of special initiatives involving the conversion of Article 16 clinics to rate-based HCBS waiver programs. OPWDD is also collaborating with the NYS Department of Health (DOH) to develop a joint certification process for clinics. OPWDD provides assistance to provider agency staff with issues related to Medicaid documentation and billing for Article 16 clinic services, and program and policy technical assistance to DDSOs dealing with clinic issues.

A new rate setting methodology, called Ambulatory Patient Groups or APGs, has been introduced to replace the current flat "per-visit" outpatient payment methodology for providers licensed through and services provided under Article 28 of Public Health Law. Clinic providers licensed by OPWDD, the Office of Mental Health (OMH) and Office of Alcoholism and Substance Abuse Services (OASAS) will also transition to the APG payment methodology. OPWDD participates in the Mental Hygiene Workgroup, coordinated by DOH, which is developing the APG structure for future implementation. APG Medicaid payment methodology will replace the regulatory fee schedule reimbursement for services provided by OPWDD-certified Article 16 Clinics. OPWDD anticipates that, as with DOH ambulatory care payments, full use of APG payment methodology for Article 16 clinic services will be phased-in over a four-year period.

The APG Medicaid payment methodology will reimburse differential amounts for Article 16 clinic services based on the resources required for each service provided during a clinic visit. An Article 16 clinic visit will be

generally defined as a "single date of service" and will include reimbursement for approved clinical services as outlined in 14 NYCRR Part 679.3 (j).

Medication Management

OPWDD intends to foster autonomy and skill development in individuals with developmental disabilities. The ability to self-administer medication is often a determining factor in decisions regarding living situations, vocational choices and leisure time/vacation opportunities. During the period of this Plan, OPWDD will expand its efforts in the use of technology to enhance the ability of individuals to self-administer medication and develop policies and regulations to facilitate medication management.

OPWDD staff members continue to provide technical assistance to agencies on the new self-medication administration and new self-medication management assessments. The forms, instructions and frequently asked questions have been posted on the Health Resources Center on the OPWDD website.

Two medication administration regulations were drafted: One (revised 633.17) pertains to medication administration in certified residential and day programs, while the second (new 697.12) pertains to the administration of medication in family care homes. Both regulations were reviewed and discussed with the Nursing Management Team Community of Practice, the Family Care Nursing Community of Practice and the Medical Directors Community of Practice. The regulations are currently being prepared for distribution to the provider associations for review.

Nutrition

OPWDD Nutrition Services is adopting the American Dietetic Association's Nutrition Care Process (NCP) statewide to enhance clinical nutrition services to individuals with developmental disabilities. NCP is a comprehensive approach to providing high quality nutrition care. The four components of the process are nutrition assessment, nutrition diagnosis, nutrition intervention, and nutrition monitoring and evaluation. The process incorporates a common language and terminology that allows clinical nutrition practice to be more measureable and consistent.

Plans are underway to implement NCP with a committee of dieticians and other staff heading up the initiative. The committee developed plans, materials and tools for workforce training. At the end of 2009, every DDSO received individualized on-site training pertaining to NCP during which dieticians learned how to apply specialized tools in their regions, as well as methodologies to enhance the provision of nutrition care.

In addition to training, OPWDD piloted a new nutrition assessment form in each DDSO. As a result of the pilot, the form will undergo some revisions and will be used by dieticians in Fall 2010. The final rollout of NCP will greatly benefit individuals with developmental disabilities and provide a more collaborative interdisciplinary process for providing nutrition care statewide.

Performance measures

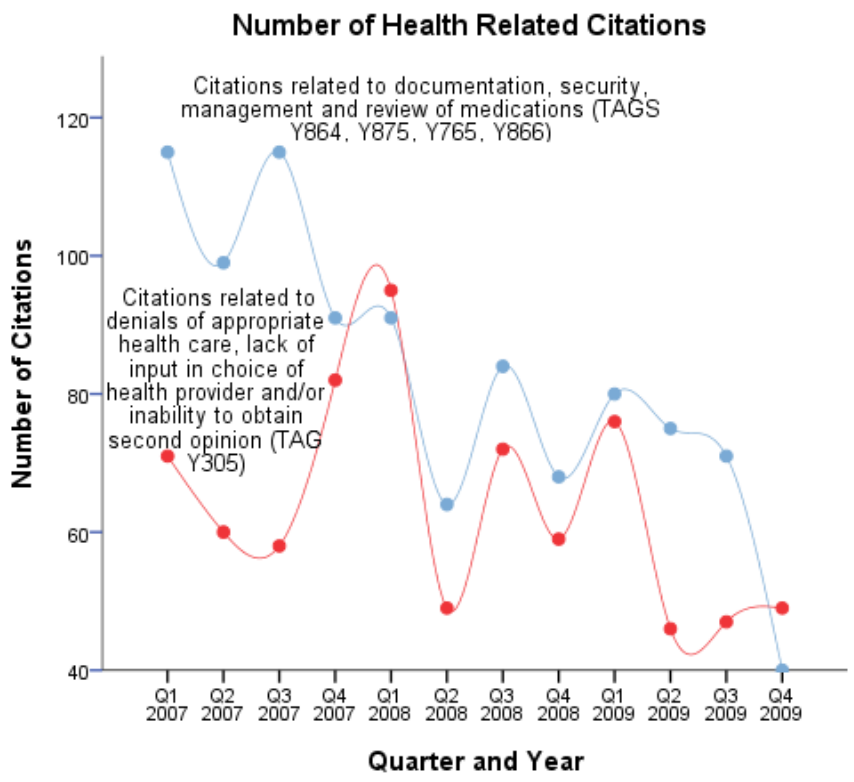
OPWDD is committed to providing high quality clinical services. These are expected to help improve basic health and to be tailored to the unique and complex clinical challenges of people we support. Currently, we

are making progress in developing indicators that provide feedback about the overall health of people in OPWDD's service system. These indicators are related to some of the initiatives underway, but are intended to be broad, overarching indicators tracked on an ongoing basis. Indicators about satisfaction with and choice of health care professionals, wellness indicators and measures targeting adequacy of medication management will be trended to provide some information about the quality of health experienced by people receiving services through OPWDD. Specifically, OPWDD will track:

1. Satisfaction with heath care professionals.
2. Distribution of people across BMI (Body Mass Index) categories.
3. Citations related to:
    a. Denials of appropriate health care including choice of health provider and/or ability to obtain a second opinion.
    b. Inappropriate documentation, security, management and/or review of medications.

The trend for the third metric can be found below. Longitudinal data are not yet available for the first and second metrics.

Metric 3.



OPWDD tracks the number of deficiencies that pertain to specific regulatory mandates. Common deficiencies include those that are related to medication and those related to choice in health care. The sum of failure to meet requirements for four different indicators was used as a broad measure of cases of medication mismanagement (blue trend line). The red trend line tracks the number of deficiencies in health-related choices. Over the past two years both have generally trended downward.

Chapter 8: Overarching Themes and Initiatives

Institute for Basic Research in Developmental Disabilities

OPWDD's Institute for Basic Research (IBR) was established under the Mental Hygiene Law to research the causes, treatment and prevention of developmental disabilities, and in some ways is the culmination of all that is in this plan. As a premier research facility with specialties including genetics and autism research and treatment, IBR is both central to and a driving force in OPWDD's ability to achieve its mission. IBR plays a vital role in the early identification, prevention and treatment of health and disability conditions. And beyond research, IBR's Jervis Clinic has a significant role statewide as well as being an important resource to the metropolitan area for assessment and evaluation, diagnostic services and genetic counseling.

Two recent examples of the critical work ongoing at IBR and related breakthroughs:

- IBR scientists reported the discovery that the earliest signs of autism may be present in babies as young as one month old. Based on a study of babies graduating from neonatal intensive care units (NICU), it was found that those later diagnosed with ASD were more likely to have had abnormal muscle tone and differences in their visual processing when assessed in the NICU than babies who went on to develop normally. Publication of this discovery has found distribution and recognition in both the scientific and popular media.
- IBR scientists participated in the largest randomized drug trial related to the Fragile X syndrome, the most common inherited cause of intellectual disability and autism. This targeted treatment trial, based on recently discovered molecular defects in the syndrome and using the GABAergic drug Arbaclofen, showed positive results. The outcomes of this study will lead to new methods to treat this common disorder and possibly some types of ASD.

Expanding IBR's mission to promote education in the field of intellectual and developmental disabilities, IBR recently entered into a memorandum of understanding (MOU) with State University of New York (SUNY) Downstate Medical Center for doctoral and masters level collaborative research and education programs in Developmental Neuroscience. Under this agreement, IBR and SUNY Downstate will provide a coherent educational framework in which didactic, clinical and research programs in neuroscience, genetics, pathology, pediatrics, and neurology will be linked to state-of-the-art knowledge in the field of developmental disabilities. The goal of this partnership is to enhance the quality of medical, diagnostic and treatment services to individuals with developmental disabilities.

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

IBR will continue to lead the way as OPWDD seeks to fulfill its mission to help people with developmental disabilities lead richer lives and realize its people first vision.

Autism Spectrum Disorders

In May 2008, OPWDD issued its Autism Platform, a comprehensive plan for addressing the significant needs surrounding the increase in individuals diagnosed with ASD. The Platform described OPWDD's planned activities related to autism as they fell into five categories. Over the next two years, OPWDD identified and pursued key initiatives within the platform that would constitute its initial focus. One key initiative was the facilitation of a NYS Interagency Task Force on Autism, co-led by OPWDD and the NYS Education Department. The Task Force included representatives from 11 state agencies and undertook a comprehensive examination of current issues related to ASD and the ways NYS has responded. In January 2010, the Task Force issued a report with detailed findings and recommendations to the Governor, the Legislature, the Board of Regents and the Inter-Office Coordinating Council. As part of that report, OPWDD prepared and submitted a status report on the progress made in implementing the 2008 Autism Platform.

In early 2010, OPWDD revised its Autism Platform to reflect the findings and recommendations of the Autism Task Force. With an updated Platform, OPWDD will continue to make improving New York State's response to the needs of those with ASD an agency priority. 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 the state's ability to effectively and appropriately support individuals living with ASD.

ASD Training The revised Autism Platform commits OPWDD to implementing an extensive slate of ASD training initiatives to make sure employees of the OPWDD service system have access to consistent, up-to-date training regarding ASD that is relevant to their work. These initiatives range from developing and implementing new statewide parent and caregiver training to address behavior challenges and expanding the cross systems training known as "Navigating Two Systems" to include multiple service systems and services for children.

Sharing Information Disseminating information about ASD and OPWDD services remains a priority activity within the revised Autism Platform. OPWDD will add several new initiatives that derive from the recommendations of the Autism Task Force. Two key initiatives include OPWDD's leadership in the expansion and maintenance of the new NYS online autism resource, NYACTS (www.nyacts.com) and in a multi-agency ASD public awareness campaign also newly underway. In addition, OPWDD will engage in new efforts to describe and disseminate critical information related to services and ASD trainings and seek to do so in ways that address language and technology barriers.

Improving the Service System Improving the OPWDD service system to provide effective services to individuals with ASD and their families is an essential component of OPWDD's Autism Platform. As OPWDD improves its system for those on the autism spectrum, it also enhances the services that are available to support any qualifying individual with or without an ASD diagnosis. OPWDD is undertaking focused projects that will grow staff understanding and use of evidence-based best practices. OPWDD supports the ongoing development of clinical best practice guidelines for the assessment and diagnosis of ASD and positive approaches to addressing challenging behaviors, and a successful model for delivering clinical behavior intervention services in public schools. OPWDD will implement new In-Home Behavioral Services, develop a model for successful supported employment for individuals with ASD, and find ways to improve the sharing of data with other service systems to facilitate smooth system transitions for individuals.

Advancing Research OPWDD recognizes the essential link between scientific research and the development of safe and effective treatment and services. Scientists and researchers at IBR continually pursue a wide-

ranging slate of basic and applied studies with significant implications for future treatment. Areas of exploration and discovery continue to include genetic and environmental causation, brain morphology, the potential for new pharmacologic interventions, and the potential to develop laboratory bio-markers for early detection of ASD.

The Autism Task Force noted the need for ASD research that grows shared understanding by uniting government and private sector resources to maximize impact and advancement. OPWDD's Autism Platform commits the agency to developing and maintaining: relationships with private sector researchers via shared ASD projects, developing a meaningful agenda of applied studies within IBR's Autism Treatment Laboratory and a clear channel for this research to support improved practice and service delivery statewide, and pursuing a full slate of ASD research projects.

Dual Diagnosis

As indicated earlier, the number of individuals with dual diagnoses of developmental disability and mental illness continues to increase steadily statewide. One of the key components of providing quality services and treatment to these individuals is to ensure that clinical staff stay up-to-date on new and advanced treatment methods.

To better prepare clinicians to address the needs of adults with dual diagnoses, OPWDD hosted a four-part video conference training series entitled *Comprehensive Assessment of Older Persons with Developmental Disabilities*. The series focused on developing expertise in the assessment and treatment of older individuals with developmental disabilities and psychiatric disorders. The trainings have been offered through the OPWDD training catalog and were open to registrations from the OMH and OPWDD certified provider agencies. Three of the four sessions have been delivered, including *Comprehensive Assessment and the Dementias*; *Medical/Neurological and Nursing Assessment*, and *Functional Skills and Cognitive Assessment*. The fourth session, *Differential Diagnostics and Case Conceptualization*, will be held in fall 2010.

In addition, clinical staff organized two other trainings entitled *Psychological Assessment Tools for Individuals with Dual Diagnoses* and *The Use of Advanced Behavioral Techniques for Individuals with Dual Diagnoses*. These trainings were presented by an internationally recognized expert and targeted psychologists and other clinicians as the audience. The Public Service Workshops Program (PSWP) of Rockefeller College sponsored the events, which were open to other state agencies, including OMH, Office for Children and Family Services (OCFS), Department of Correctional Services (DOCS), and Division of Criminal Justice Services (DCJS).

Dialectical Behavior Therapy

Dialectical Behavior Therapy (DBT) is an evidence-based treatment that was first developed to treat individuals who engaged in self-injurious behavior and who were diagnosed with Borderline Personality Disorder. The DBT approach has recently been applied to treating individuals with depression, eating disorders, suicidal and assaultive behaviors, chronic pain, and other complex problems. DBT-based practices are being utilized to help individuals with developmental disabilities throughout the United States.

OPWDD initiated multiple training activities on the use of DBT in late 2009 and 2010. These efforts included quarterly statewide videoconferences for clinicians who are actively involved in or learning about utilizing DBT approaches with individuals who have developmental disabilities. Innovative methods for

implementing DBT practices in different DDSOs were presented, with follow-up reports on the individuals' responses to treatment. Team members from participating DDSOs continue to support and offer review, peer supervision and consultation to one another, in order to share ideas and progress on specific projects and to contribute solutions for concrete, local therapy-interfering factors. One DDSO is developing an online staff education/training program on the rationale and supportive techniques related to DBT treatment approaches. These approaches utilize mental and physical techniques to increase distress tolerance and regulate emotions.

OPWDD maintains a clearinghouse of resources for the implementation of DBT. Resources continue to be distributed to clinicians, including recent journal articles, literature reviews, and other treatment-relevant information on the application of DBT to special populations, including a training manual and curricula from national sources.

Children Residing Out-of-State

Billy's Law, passed in 2005, seeks to return children placed into private residential schools outside of the state back into New York State, and to create the in-state infrastructure sufficient to accommodate the future needs of children. According to the report of the Interagency Out-of-State Placement Committee, as of December 2009, 676 children remained in out-of-state private residential schools. This number represents a reduction from the 1,200 children living out-of-state at the time that Billy's Law was passed. The law established the Out-of-State Placement Committee, which then created several workgroups to analyze and report to the committee on several action steps pertaining to infrastructure, model process, contract development, and a registry of schools. In response to the enactment of Billy's Law, NYS undertook the multi-agency initiative of developing needed infrastructure. OPWDD and SED began the joint development of 255 children's residential program (CRP) opportunities. Sixty-six of those opportunities are already available, with another 50 being made available in 2010-11.

Several OPWDD/SED joint projects created new in-state opportunities while another group of similar OCFS/SED joint projects will be developed for children with other disabilities. 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.

Aging Out

Since the passage of new laws in 1996, OPWDD has the responsibility of planning for children who are aging out of their juvenile placements in private residential schools or foster care. In 2010 OPWDD launched a new data system to enhance the local planning process for these children. The aging out data system is maintained by each DDSO, integrated in a centralized system for gathering statewide data. This resource will serve as a tool for DDSO staff as they work with young people and their families to plan for appropriate adult services.

Children represent more than one-third of the people served by OPWDD. Since the most natural setting for children is their family home, the majority of OPWDD services to children are delivered at home. OPWDD's focus on providing services for children in their own home is in keeping with the Coordinated Children's Services Initiative (CCSI). CCSI establishes an expectation that children receive appropriate services in their home, in their community and from their home school district.

An important venue for interagency coordination for children's issues is the Children's Cabinet. The 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 multiagency approach to increase access to Child Health Plus, OPWDD provided training to virtually all service coordinators on how to access "facilitated enrollers" in Child Health Plus. The agency has also engaged in an outreach campaign to enroll not only children with developmental disabilities but their siblings in Child Health Plus, in an effort to expand health care to the families we serve.

OPWDD Commissioner's Advisory Council includes a subcommittee focused on the educational needs of children with developmental disabilities. The membership includes family members and professionals from around the state. Among its accomplishments is the creation of a special education curriculum that is offered as a professional development option for service coordinators several times annually by instructors from the Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD). The committee is also involved in promoting notification to children about to transition from school of the availability of specific services provided by OPWDD.

Children with Complex Medical Needs

OPWDD operates three Care-at-Home (CAH) HCBS waivers under authority granted by section 1915 of the Social Security Act. Services to children with severe developmental disabilities and complex medical conditions living at home with their families are provided through the OPWDD CAH waivers (III, IV and VI). Almost 600 children are currently enrolled in the OPWDD CAH waivers. Each CAH waiver is renewed by CMS every five years. CAH IV and VI were renewed in 2007 and CAH III was renewed in 2009.

Children who are enrolled in the OPWDD CAH waivers may receive three waiver services: case management, respite care and assistive technologies/environmental modifications. In addition, Medicaid State Plan services are available to children using CAH, whose Medicaid eligibility is determined without taking into consideration the income and resources of their parents.

Medicaid Service Coordination

In NYS, Medicaid Service Coordination (MSC) is the primary means of connecting individuals with developmental disabilities to services and supports in their community. The foundation for MSC is informed choice: the Medicaid Service Coordinator's responsibility includes helping each individual to gain knowledge and understanding of all aspects of the area in which he or she is making a decision.

The definition of informed choice adopted by OPWDD is as follows:

- A person has made an informed choice when he or she has made a decision based on a good understanding of the options available and a good understanding of how that choice may affect his or her life.

- A person can make an informed choice on his/her own, or may ask family members, friends or others for assistance if the individual needs help making a good decision. Informed choices can be about everyday things like what to wear, or life-changing decisions about where to live, what kind of work to do, or who to be friends with. These decisions can also be about what kinds of services or supports someone wants or needs, and where and how to get them.
- When making an informed choice a person should understand the possible risks involved and what can be done to reduce the risks. A person should also realize that his/her ability to make choices may change over time, or may be different for different kinds of decisions.
- Personal choices should be respected and supported by others involved in the person's life.

Within this framework of informed choice, service coordinators are responsible for working with individuals and other stakeholders to write and update the Individualized Service Plan (ISP), review habilitation plans, assist in accessing public benefits, and advocate for individuals and their families. Currently, service coordinators assist approximately 74,000 individuals, making MSC one of the largest service coordination programs in the country. Like most services, the MSC program has evolved and incorporates changes based on feedback from service participants, service coordinators and providers.

In Spring 2008, OPWDD, in collaboration with the Informed Choice Design Team and other stakeholders, embarked on a comprehensive review of the MSC Program. The goal of this effort was to develop recommendations to guide the redesign of MSC. Driven by informed choice and the desire to create a financially sustainable program, OPWDD expedited implementation of a MSC restructuring plan to ensure the future integrity and sustainability of MSC services, as well as achieve State Fiscal Year 2010-11 savings.

The ability to preserve MSC and all OPWDD services requires innovation, efficiency and a viable strategy. The intent of the MSC changes effective this Fall are to:

- Allow for more efficient, flexible and cost-effective service delivery;
- Enable services to be better tailored to individualized needs, wishes and outcomes within the scope of the program; and
- Continue to ensure that informed choice and individual and family desires are taken into account to the greatest extent possible.

With these principles in mind, OPWDD accelerated its work in partnership with all stakeholders to target aspects of the MSC program, other than those subject to court order, that warrant change. The resulting recommendations focus on enhancing the MSC program's responsiveness to individual needs while eliminating requirements, especially paperwork, that impact on a service coordinator's workload with little or no benefit to participants. The overall objective is for the MSC program to be as flexible as possible, so that each person receives the needed amount of assistance from his or her service coordinator, at the right time, in the right place and at a sustainable price. The major changes to the MSC Program are:

- Reduction in required paperwork and/or streamlining of MSC forms and documentation (e.g., monthly note, Service Coordination Agreement, ISP, elimination of filing Service Coordination Observation Report (SCOR) for other than Willowbrook class members).
- Increased flexibility with regard to the tools used to provide appropriate MSC services (i.e., face-to-face service meetings; in-home visit requirements; maximum caseload size).
- Establishing criteria for and streamlining transition payments.
- Utilizing quality outcomes/indicators in program reviews to assist MSC providers to make quality improvements.

- Increased flexibility in MSC billing standards.

Although there will be many changes, some components of the MSC Program will remain constant, such as:

- Outcomes and expectations for MSC including informed choice and individualized and person-centered service provision.
- The scope/functions of MSC.
- Eligibility criteria for the service.
- Qualification requirements of service coordinators and supervisors.
- Delivery of MSC by not-for-profit providers pursuant to a contract with OPWDD.
- Court-ordered MSC requirements for Willowbrook class members.

Overall, OPWDD's goal is to improve the efficacy of the MSC program and ensure that service coordination is designed to meet the needs of the diverse individuals and families that receive supports through OPWDD.

Forensic Services

In NYS there is a small population of individuals with developmental disabilities involved in the criminal justice system or engaged in serious offending behaviors. Some of these individuals need intensive treatment and supports from OPWDD to address the issues that interfere with their ability to live independent, productive lives. In providing services and supports to the forensics population, OPWDD strives to maintain its commitment to helping people with developmental disabilities live richer lives.

Intensive Treatment Options (ITOs), including Centers for Intensive Treatment (CITs), Regional Intensive Treatment (RITs) programs and Local Intensive Treatment (LITs) programs, provide fully individualized services for all participants through treatment planning processes that are centered on the unique needs and aspirations of the individual and encourage the participation of the individuals and their families. OPWDD encourages individuals who reside in ITOs to participate in self-advocacy groups and involve the local self-advocacy group in the decision-making and policy-setting functions of the program.

OPWDD recently reconstituted the leadership community that is responsible for reviewing the referrals of all individuals for whom placement into an ITO is sought. The new group, the Referral Support and Vacancy Planning (RSVP) Committee, includes representatives of each ITO as well as both of the OPWDD Regional Offices and the Bureau of Forensic Services. The RSVP Committee reviews the referral of every person being considered for possible admission to an ITO program to verify that the individual is eligible for OPWDD services, meets the federal level of care requirements, and has current challenging behaviors that can be most appropriately addressed in an ITO program. The RSVP Committee also has responsibility for managing the ITO residential capacity so that those individuals who are most in need of the intensive treatment and support of an ITO program receive the opportunity in a timely manner. By managing the referral and resource management function, the committee makes better decisions regarding each individual and maximizes the effectiveness of the ITO resources across the entire system of services.

Another initiative concerns the enhancement of the process used to transition individuals from an ITO to a less intensive setting. The ITO Placement Taskforce consists of designated staff from each ITO, the Bureau of Forensic Services and the Regional Offices. The Taskforce is responsible for establishing and maintaining a list of all individuals being served in ITOs who have been deemed ready, now or in the near future, to move to a less intensive, less structured setting. The Placement Taskforce tracks the referral of each individual, identifies

any impediments to movement and resolves issues as soon as such a move is deemed clinically appropriate. The Placement Taskforce also works closely with the Regional Offices in the allocation of CPP resources so that local DDSOs receive the funding they need to develop appropriate community placements for individuals from their regions. In this way, community based programs will be available when individuals are ready to return to their home regions.

In addition to these recently instituted practices, OPWDD has collaborated with Department of Correctional Services (DOCS) in developing a proposal to the DDPC to fund a discharge planner who will assist inmates of DOCS Special Needs Units for individuals with developmental disabilities to transition from prison to community living. Historically, one of the biggest challenges has been obtaining medical and other historical records for the OPWDD eligibility determination process. To meet the eligibility requirements there must be documentation that indicates a person had a developmental disability before age 22. Previously, DOCS has not had staff available to track down historical records and assist with the eligibility process. The Discharge Planner will ensure that those eligible for OPWDD services have a comprehensive discharge plan in place by the time of discharge. In three years, DOCS and OPWDD hope to serve 30 individuals through this effort.

Workforce Development

Direct Support Workforce (DSW) Advisory Committee

The 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.
- Develop a plan to address future workforce needs.

The DSW Advisory Committee contracted with a consultant to assist with strategic recommendations based on research and analysis of workforce data currently available. Additionally, the DSW Advisory Committee partnered with the New York State Association of Community and Residential Agencies (NYSACRA) and Self-Advocacy Association of New York State (SANYS) to facilitate a second round of forums with direct support professionals. A report summarizing the focus group findings is available at:
http://www.nysacra.org/nysacra/news/Voices_Frontline_II.pdf

Talent 2020 Platform

In an effort to develop and implement mechanisms that will ensure that OPWDD can attract, hire, deploy, fully engage and retain the most talented staff, OPWDD will implement the *Talent 2020 Initiative*. The initiative will focus on three main areas: Talent Recruitment, Talent Development, and Talent Retention. The key objectives for each focus area are outlined in Table 2.

Table 2. Talent 2020 Objectives

Talent Recruitment	Talent Development	Talent Retention
• Review recruitment strategies • Improve community outreach • Increase marketing	• Develop orientation • Improve on-boarding of new employees • Identify skills needing to be developed • Identify how to best develop people • Evaluate current and future programs to measure effectiveness	• Identify strategies to retain good talent • Improve succession planning • Develop career paths

Transforming the workforce of a large organization such as OPWDD is an ambitious initiative. To meet these long-term objectives, OPWDD will take the following action steps over the next few years:

- Establish an agency steering committee charged with leading the initiative.
- Establish a set of targets and performance measures for evaluation.
- Develop and implement a training curriculum to support workforce transformation and shift the organizational culture.
- Review the qualifications for the direct care title series.
- Assess the support available to the direct care workforce.
- Review core competencies.
- Evaluate existing recruitment methods.
- Align workforce planning efforts with recruitment and retention strategies.
- Provide a positive and supportive work environment.

Fresh Air 2010

OPWDD established a committee to promote smoking cessation programs to support individuals who wish to quit their use of and dependence on tobacco products. The specific charge of this committee was to:

- Reduce the use of tobacco products by individuals and staff.
- Provide enhanced access to smoking cessation resources for individuals and staff.
- Examine the issues associated with OPWDD becoming a tobacco-free agency and develop recommendations to positively impact this area.

As part of this initiative, OPWDD convened a sub-group that includes representatives from unions, the Employee Assistance Program (EAP), OPWDD medical staff, the Commissioner's Advisory Board for the Willowbrook class, and DDSO representatives to examine issues specifically related to smoking cessation in the workforce. Additionally, OPWDD will continue to engage unions in labor/management discussions with the goal of becoming a totally tobacco free agency.

Quality Management

OPWDD engages in continuous efforts to implement a comprehensive statewide quality management strategy. This strategy is based upon a commitment to shared leadership, learning and organizational development. This commitment builds capacity throughout the system to enhance the quality of services for individuals with developmental disabilities so that they can live richer lives. Quality management and continuous quality improvement processes are integrated at all levels into the ongoing and daily operations of the OPWDD system.

OPWDD is developing and implementing quality improvement strategies to assess and improve supports and services, and to address the Quality Improvement Strategies indicated in the HCBS waiver agreement. OPWDD is also developing a system of metrics to assess the quality of OPWDD and provider agency supports and services. A database will aggregate on-site and agency findings from quality reviews.

OPWDD implemented new quality management principles to complement traditional regulatory and enforcement procedures, and plans to redesign the survey process. Review activities will continue to assure the safety and welfare of individuals with developmental disabilities, and will incorporate a "People First" approach to assuring and improving quality services and individualized outcomes. The revised survey process will better promote the core values expressed in OPWDD's vision and mission statements by increasing focus on individual satisfaction and agency effectiveness. The new process will also promote agency self-monitoring.

OPWDD will use the expertise of the designated COMPASS agencies as an advisory panel to design and pilot a revised survey process. OPWDD staff, including staff from the DDSOs, will form advisory panels comprising individuals with developmental disabilities, their families, advocates, and providers of services in order to develop improved survey protocols. These protocols will focus on person-centered values and the four priority outcomes of home, health, productivity, and relationships. Staff routinely hold forums, attend self-advocacy meetings and attend provider consortium meetings to obtain input from all stakeholders. OPWDD is developing a communication initiative to inform all stakeholders of current issues, initiatives and best practices.

Incident Reporting Management Application

The web-based Incident Reporting Management Application (IRMA) has been fully implemented within state-operated programs in all districts, and the implementation of IRMA among voluntary operated agencies has commenced. IRMA provides the ability to capture data from OPWDD incident reporting forms and follow-up information related to incident investigations. IRMA will benefit the field by enhancing OPWDD's capacity to identify trends related to incidents and generate reports. Analysis of incident data will be used to guide the development of targeted safety awareness campaigns for people with developmental disabilities. In addition, OPWDD will use data from IRMA to develop an individualized, risk-based strategy for the review of incident management at provider agencies.

Surveys and certification

To ensure that provision of services is in compliance with established laws, regulations and policies, OPWDD conducts reviews of all programs and services for the safety and welfare of individuals served. When deficient practices are identified, OPWDD staff ensures that appropriate remedial actions are taken. OPWDD has begun a process to integrate the recommendations of the expert panel on fire safety into the quality management

review process. Also underway is the development of targeted review protocols that will promote OPWDD's core values and allow for data collection and analysis to evaluate progress toward implementing the transformation agenda. OPWDD staff has provided training to provider agencies regarding the requirements of a Medicaid Compliance Program as required by the NYS Office of Medicaid Inspector General (OMIG). Limited fiscal reviews will include a review of agencies' compliance with policies and procedures.

Systems and performance accountability

In October 2010, the OMIG will assume responsibility for all billing and claiming audits for OPWDD's provider agencies that utilize Medicaid funding. OPWDD is committed to maintaining a strong internal focus on fiscal systems, performance accountability and continuous improvement in the programs it operates. Technical assistance will be provided to state-operated programs that will ensure the implementation of quality management self-assessment systems to strengthen program integrity and bring greater fiscal accountability. OPWDD will also continue to conduct Limited Fiscal Reviews at our not-for–profit agencies focused on board governance, internal controls, agency corporate compliance policies and procedures including personal allowances, adherence to regulatory filing requirements, and fiscal viability.

Over the next five years, OPWDD will seek to assess the degree to which provider agencies have developed and implemented quality management self-assessment systems that provide mechanisms to strengthen agency governance, program integrity and fiscal accountability. OPWDD will focus on the review and audit of various contracts (CSS, FSS, ISS, environmental modifications, Voluntary Preservation Funds, etc.) awarded to provider agencies and vendors for the delivery of services and supports. Compliance with state bidding and procurement regulations and best practices will be reviewed and internal controls evaluated, as well as the provider's general corporate operations related to the terms of the contract/agreement. OPWDD will examine and assess the provider's expenditures under contract to determine adherence to the budget; that expenditures claimed under contract were actual, reasonable and necessary to the provision of services funded by the contract; and that they were properly reported.

Interagency Initiatives

Charged by stakeholders of the health and mental hygiene systems during the "People First" Coordinated Care Listening Forums in 2007, OPWDD, OMH, OASAS and DOH have been striving to increase collaboration and improve the coordination of services for individuals served by multiple agencies. 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. The following section illuminates the shared commitment by all of the agencies to ensure that people come first. The final report 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 the three Department of Mental Hygiene agencies, (i.e., OMH, OPWDD, and OASAS), was re-established to eliminate barriers and improve coordination of services for people with disabilities. The agencies agreed that the IOCC would meet regularly to address issues of an interagency nature focusing on access and coordination of services. They also agreed that the OASAS Commissioner would assume the duties of IOCC Chairperson, each Commissioner would appoint an agency coordinator, and 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 meets four times during the year. The IOCC's web page is available at http://www.oasas.state.ny.us/pio/collaborate/IOCC/ .

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, CQCAPD and DDPC to serve as ad hoc members. Their involvement and input has been 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.

Integrated Mental Hygiene County Planning

The CLMHD, along with OMH, OASAS and OPWDD, have made good progress in developing an integrated approach to local planning. Historically, each New York 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 is to strengthen the service systems and promote coordinated care by better identifying and addressing local needs while improving services for people with developmental disabilities and people confronting addiction, gambling problems, or mental illness. The integrated approach to local planning provides for improvements in the quality of care 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 agreed to 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 OPWDD into one 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 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 movement toward more integrated services. Designed to streamline the planning process by eliminating duplicative paperwork, the system also encourages localities and state agencies to think and plan across systems. In 2010, as part of the third year of implementation, the Planning Committee made a number of enhancements to the system to improve its relevance to state planning and improve data analysis.

Most Integrated Setting Coordinating Council

The Most Integrated Setting Coordinating Council (MISCC) is a statutorily created council that developed and is implementing a plan to ensure that all people with disabilities receive services and supports appropriate to their needs in the most integrated setting. OPWDD chairs the MISCC, which is composed of state agencies and 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. Since 2008, the MISCC has identified housing, transportation and employment as top priorities for its plan. OPWDD, OMH, and OASAS participate on the Housing, Employment and Transportation Committees. All have been charged with focusing on activities, outcomes, and recommendations that foster the MISCC mission. The MISCC, which meets quarterly, submits an annual report to the Governor and Legislature.

The MISCC has begun the process of transitioning to a more active planning and implementation role. This transition is evidenced by the completion of the MISCC's first ever two-year (short-term) plan to guide statewide efforts to better provide and connect individuals with disabilities to employment, housing, transportation, and long term care services. New York's Olmstead Plan (i.e., the long-range MISCC plan) will be comprehensive and will accomplish the following tasks:

- Support individuals with disabilities in the most integrated setting.
- Provide baseline data where feasible.
- Ensure quantifiable goals/objectives for the future.
- Include data on unmet needs.
- Identify a timeline for achieving goals.

The MISCC was encouraged by multiple public comments received on the draft plan. These comments have been included in the plan to the extent practical given the fiscal/economic environment. A copy of the draft plan and MISCC annual reports can be found at: http://www.omr.state.ny.us/MISCC/.

Children's Mental Health Plan

As noted above, OPWDD is actively engaged with other child serving agencies to enhance and coordinate services for children. OPWDD has worked with OMH as it updates its Children's Mental Health Plan, now known as the Children's Plan.

Through the Children's Plan OMH, OPWDD and OASAS, as well as other child-serving agency staff and stakeholders, worked to create new recommendations for promoting the mental health and wellness of young children, youth and families. The Children's Plan can be found at:
http://www.omh.state.ny.us/omhweb/engage/childrens_plan.pdf

Moreover, the result of this collaboration was the creation of the Commissioners' Committee on Cross-Systems Collaboration for Children and Youth. The committee is working to make the service delivery system and customer-experience better. For example, a subset of the Regional Technical Assistance Team (RTAT) of representatives from multiple service systems (OMH, OPWDD, OASAS, Office of Probation and Correctional Alternatives [OPCA], OCFS, DOH, SED, family representatives, Coordinated Care Services, Inc., and CQCAPD) was established. The new RTAT subgroup will be activated when a family encounters barriers in service delivery. The goal is to ensure that the barriers encountered by the child and family are resolved to the family's satisfaction. The results of each team's work will be tracked by the NYS Council on Children and Families (CCF) and reported to the Commissioners' Committee with recommendations for further changes needed to support advancement of the Children's Plan.

OPWDD is involved in several other collaborative initiatives, including:

Navigating Multiple Systems – This training builds on the success of the OMH/OPWDD program called Navigating Two Systems. Representatives from five agencies jointly developed a framework for training agency staff, local officials, providers, and families in the various roles assumed by each player in providing for the needs of a child. This training is intended to be Internet based (through agency websites) and include similarly organized segments from all agencies and family partners. The training video segments will provide local agency contact information, which will also be available electronically. This information will allow viewers to contact an agency about their needs and wants. Part of this training will offer information about advocacy groups that can assist with finding services.

Respite – Many agencies that serve children include respite in their menu of services. In many cases, when a crisis occurs there may be no respite opportunity available or readily identified that would meet the child's needs. An interagency workgroup of the Commissioners' Committee is looking into the availability of interagency respite and will recommend approaches for matching supply with demand, which might include opening availability across agencies.

Clinical Consultation Model – This model builds on the resources of OPWDD and OMH, to provide effective cross system services in areas where there are limited resources to address the special needs of children with dual diagnoses. In this model, OMH provides access to their telepsychiatry service for dually diagnosed children. In turn, and for the same children, OPWDD provides consultation on behavior therapies/interventions to address behavioral needs. A pilot of this model is being developed in OMH's Central region (OPWDD's Broome DDSO).

Older People with Developmental Disabilities

OPWDD's initiatives and policies related to aging originated from the Commissioner's Task Force on Aging, which reconvened from 2006-2009. In addition to OPWDD, membership of the Task Force represented the State Office for the Aging (SOFA), DOH, CQCAPD, DDPC, the Commissioner's Task Force on Willowbrook, provider agencies, self-advocates and parent advocates. 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.

By 2009, the Taskforce developed recommendations for aging services and supports. Some of the products in place are the Preventive Health Care Screening Guidelines for older adults, and the Aging Information Corner with information and resources on the OPWDD website. Other initiatives are underway, including the development of training to foster consistency of practice and encourage the shortest possible nursing home stay. The Aging in Community educational training initiative, made possible through a DDPC grant, has also been implemented.

As a result of collaborative efforts with SOFA to assist older persons with developmental disabilities to remain in the community, OPWDD sponsored videoconference training on agency resources, individualized alternatives to nursing facility placement, and end-of-life care. A refresher session was jointly conducted by OPWDD and SOFA at the June 2010 MSC Supervisors training.

OPWDD appointed aging contacts in each DDSO, the majority of whom participate in Interagency Aging Coalitions that encourage cross-agency training and resource sharing. OPWDD participates in the Geriatric

Mental Health Council, chaired by OMH and SOFA, in an interagency effort to advance geriatric mental health care that began with the enactment of the Geriatric Mental Health Act in 2006.

OPWDD maintains long standing alliances with SOFA, OMH and other state and voluntary agencies that will continue to encourage future collaboration and improve service delivery and planning for older adults and their families.

OPWDD will continue to work with all of its partners to ensure continuous systems improvements, increased equity of access to needed supports and services, and advancements in identification, prevention and treatment for individuals with developmental disabilities, as well as outreach and support to their families.

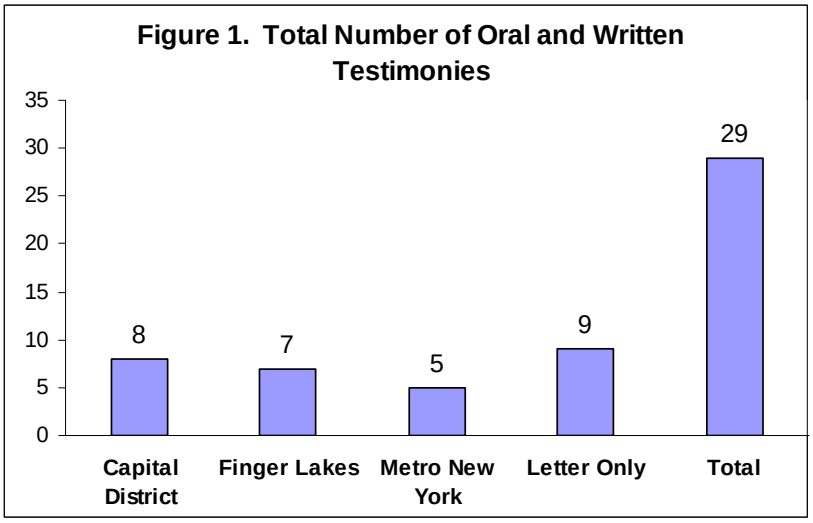
Appendix A

Summary of Public Hearing and Online Survey Feedback

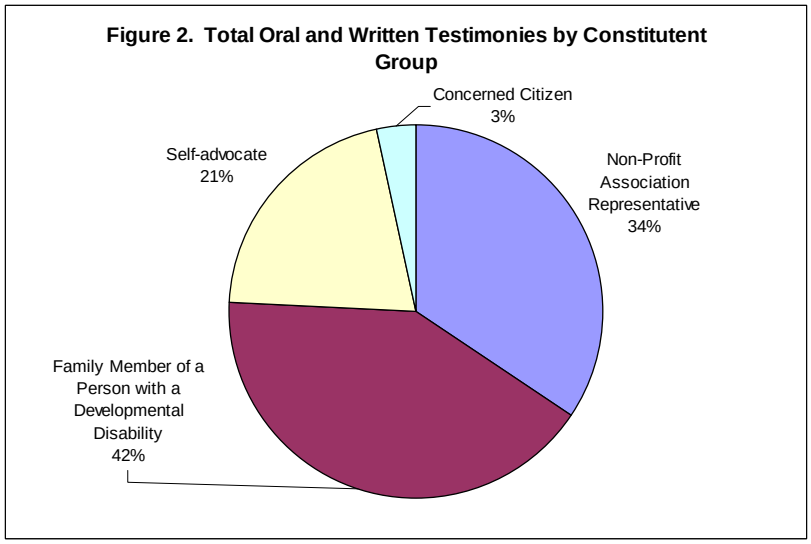
To reach a diverse population of stakeholders, OPWDD gathers public feedback for the comprehensive plan through a variety of methods. This year as last, the public had the opportunity to submit written testimony, participate in a public hearing, and/or take the on-line planning survey that was offered on the OPWDD website. Appendix A highlights the overarching themes that have been incorporated in this plan and will be used to inform OPWDD's strategic framework.

Public Hearing on the 2010-2014 Statewide Comprehensive Plan

On Monday August 23, 2010, OPWDD held a Public Hearing on the Draft 2010-2014 Statewide Comprehensive Plan. The Hearing was held at the Capital District DDSO as a live video-conference with remote sites at the Metro New York DDSO and the Finger Lakes DDSO. A total of 136 constituents attended the Public Hearing at all locations, over which Acting Commissioner Max Chmura presided. The purpose of the Public Hearing was to obtain feedback from OPWDD stakeholders and incorporate the ideas, suggestions, and comments received to further refine the Five Year Comprehensive Plan.

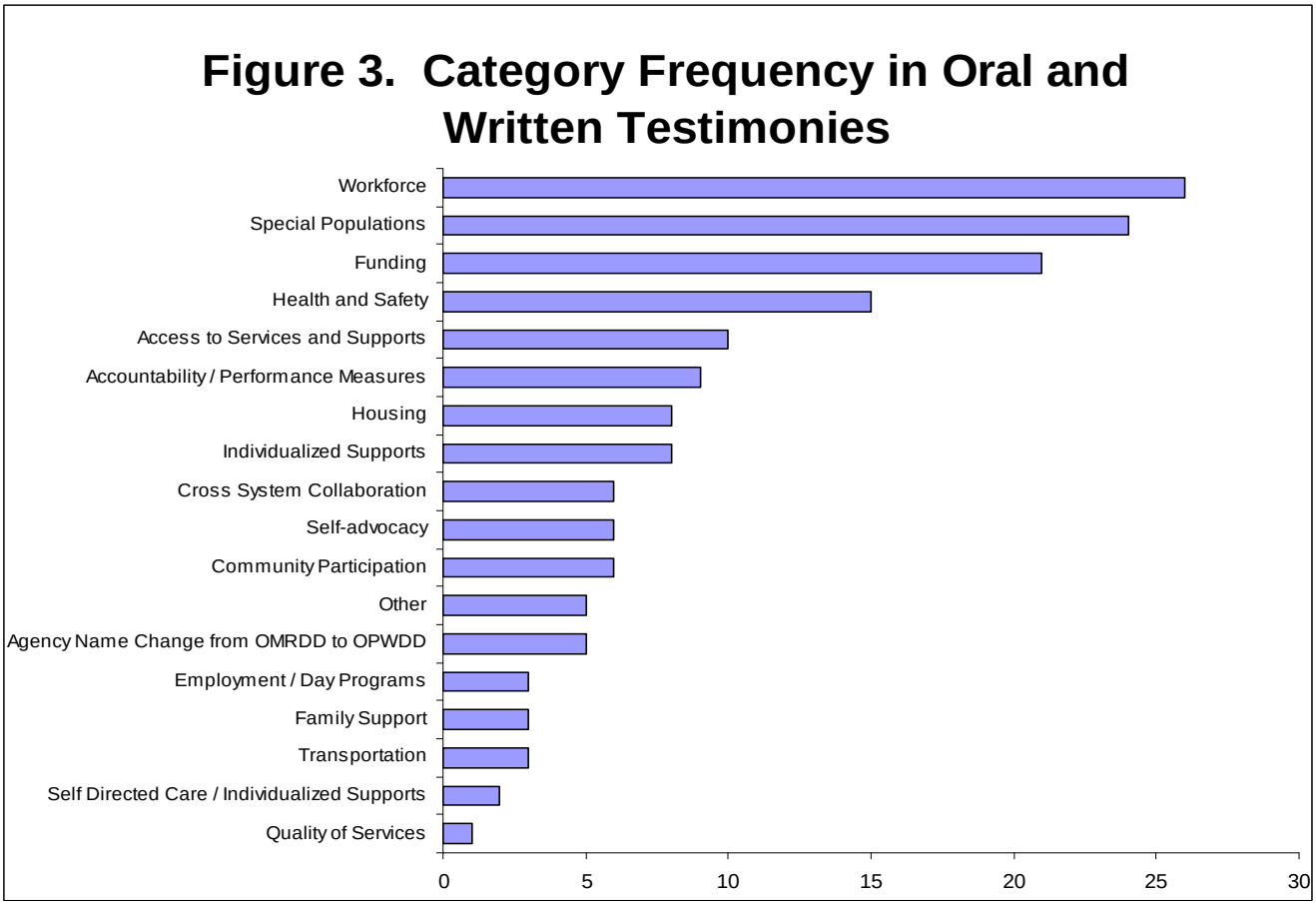


As shown in Figure 1 a total of 29 people provided testimony for the Public Hearing, including 20 speakers and nine written comments. Figure 2 shows that family members were the largest group of constituents to submit testimony to OPWDD, followed by representatives from non-profit associations and self-advocates.



There were a total of 161 separate topical comments made by individuals providing testimony. When the comments are categorized, 26 of the total comments addressed the workforce. Workforce issues for direct support professionals included:

- Background checks;
- A career ladder to help with recruitment and retention efforts;
- Concerns of increased workloads; and
- Cultural diversity.



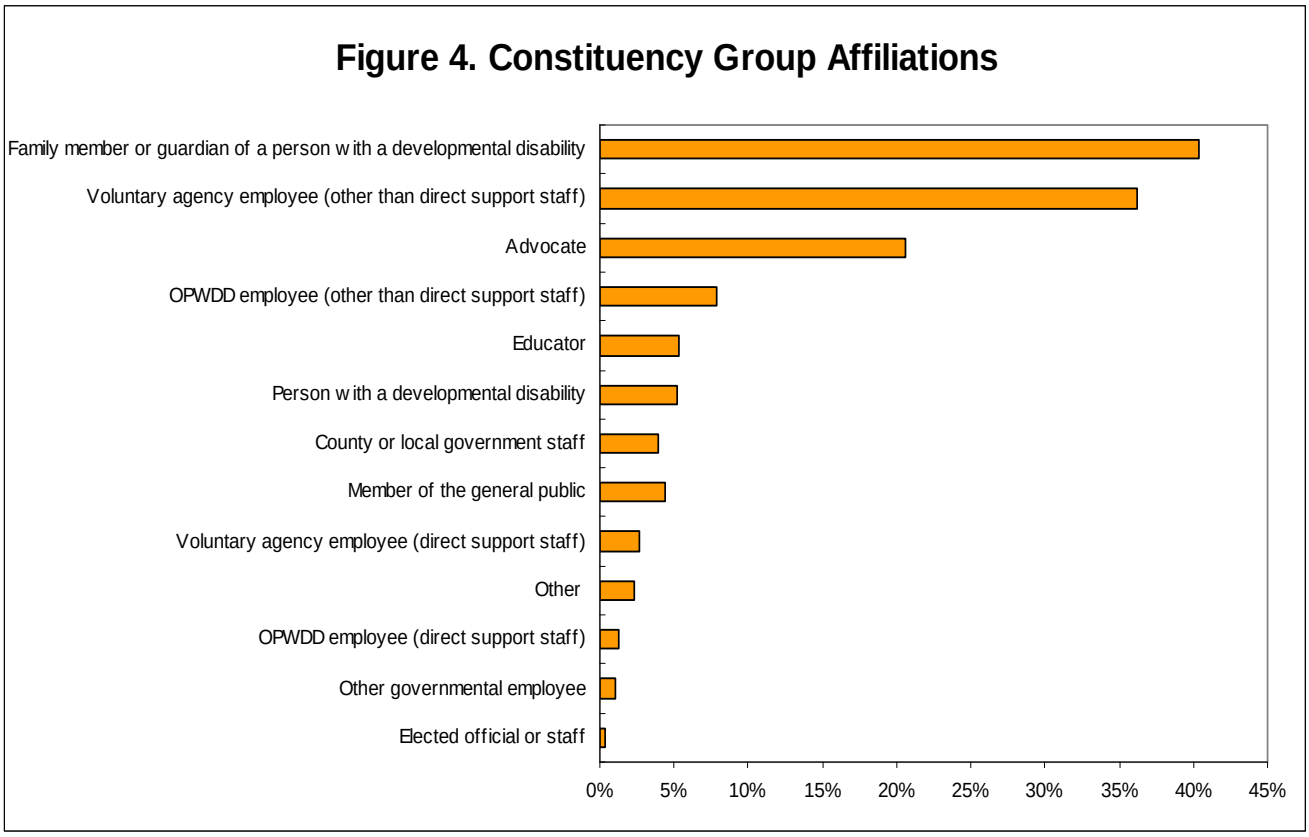
Comments regarding special populations were a close second, totaling 24. These include autism, individuals with dual diagnosis of a developmental disability and dementia, older adults, and children with fetal alcohol syndrome. Funding was also frequently discussed, with 21 comments concerning the ability to fund supports and services.

Several people discussed health and safety, access to services and supports, accountability/performance measures, and the lack of information about housing options as well as the length of time individuals have to wait for housing services. People also advocated for more cross systems collaboration with OMH, OASAS and others. Several individuals commended OPWDD on the name change and how it will lead to better lives for individuals with developmental disabilities.

On-line Survey

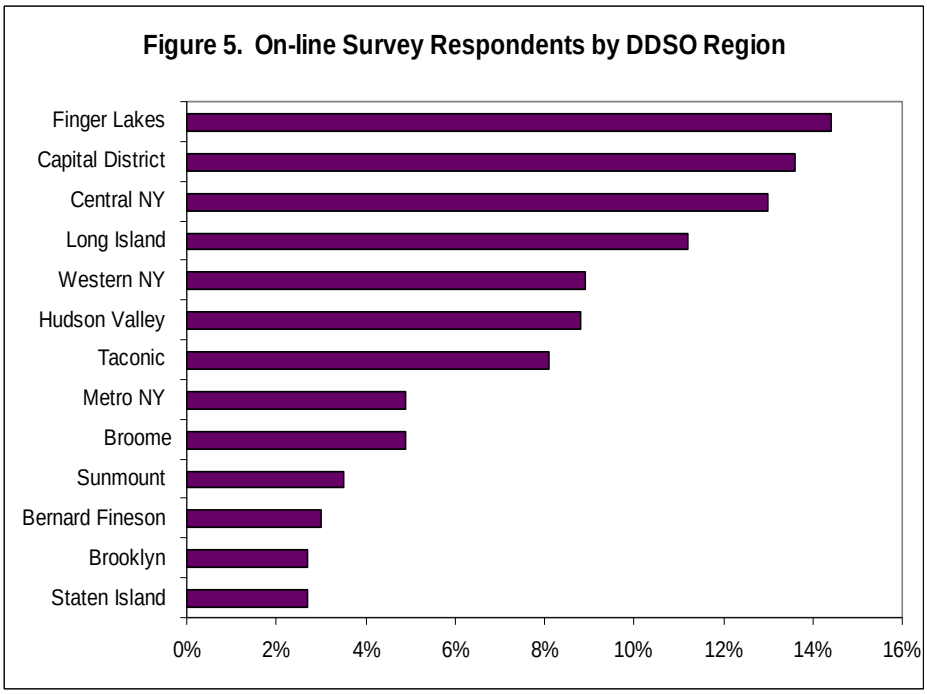
An on-line survey was available for the public from July 27, 2010 - August 31, 2010 on the OPWDD website. Respondents were asked about their:

- Affiliation with OPWDD;
- Demographic information;
- Opinion about the top eight focus areas OPWDD should prioritize during the next few years; and
- Opinion about the top eight areas where OPWDD has accomplished the most in the past few years.



Respondents also provided feedback to OPWDD about other issues related to services and supports. All responses were anonymous. Participants were able to skip items and provide more than one response to some questions.

A total of 815 people participated in the on-line planning survey. Over 97 percent of the survey respondents were New York State residents and 78.7 percent were female. Figure 4 shows that the majority of the responses were from family members or guardians of a person with a developmental disability (40.4 percent). Voluntary agency employees (other than direct support staff) were the second largest group at 36.2 percent.



When the responses are analyzed by DDSO region,

the Finger Lakes DDSO had the most responses at 14.4 percent, followed by the Capital District DDSO at 13.6.

Of the 810 respondents who answered the question: "rank up to eight focus areas that you think OPWDD should prioritize during the next few years," personalized supports and services was the highest priority among the respondents, with 50 percent ranking this within their top eight choices. Following are family supports with 46.8 percent, streamlining of regulations with 44.1 percent, and special populations with 43.2 percent. Table 1 shows the complete break-down of all responses to this question.

Table 1. Please identify the TOP EIGHT focus areas you think OPWDD should prioritize during the next few years:

Answer Options	Percent	N
Personalized supports and services	50.0%	405
Family supports	46.8%	379
Streamlining of regulations, policies and procedures	44.1%	357
Special populations, e.g. aging, dual diagnoses, autism, etc.	43.2%	350
Quality of the workforce	40.7%	330
Diverse living arrangements, e.g. living with friends, live-in caregivers, independent living, etc.	40.6%	329
Employment and community volunteer work	39.9%	323
Access to and coordination of services	36.8%	298
Behavioral health and crisis intervention	36.4%	295
Group homes	36.2%	293
Transportation	34.6%	280
Cross-systems collaboration, e.g. with Mental Health, Education, etc.	33.3%	270
Innovation in service delivery	29.9%	242
Transition from secondary education	27.4%	222
Quality management and performance accountability	26.3%	213
Individual control over supports and services	24.9%	202
Day services in group settings	24.2%	196
Housing assistance, e.g. mortgage products, rent subsidies, etc.	22.1%	179
Community attitudes and acceptance	21.7%	176
Full community participation and citizenship	21.5%	174
Electronic record keeping	20.1%	163
Relationships with staff, friends and family	16.8%	136
Self-advocacy	15.1%	122
Public information and outreach	13.7%	111
Other (please specify)	10.7%	87
Personal health initiatives, e.g. smoking cessation, nutrition, etc.	9.5%	77

In addition, the survey asked for respondents to "identify the top eight areas you think OPWDD has accomplished the most in the past few years." Of the 700 respondents who answered this question, self-advocacy was the biggest accomplishment noted at 46.4 percent. Personalized supports and services followed with 38 percent and day services in group settings with 36.9 percent. Table 2 shows the complete break-down of all responses.

Table 2. Please identify the TOP EIGHT areas where OPWDD has accomplished the most in the past few years:		
Answer Options	**Percent**	**N**
Self-advocacy	46.4%	325
Personalized supports and services	38.0%	266
Day services in group settings	36.9%	258
Family supports	35.9%	251
Public information and outreach	34.0%	238
Group homes	33.6%	235
Community attitudes and acceptance	32.0%	224
Individual control over supports and services	26.7%	187
Access to and coordination of services	25.9%	181
Relationships with staff, friends and family	23.7%	166
Employment and community volunteer work	22.4%	157
Special populations, e.g. aging, dual diagnoses, autism, etc.	22.4%	157
Quality management and performance accountability	22.1%	155
Full community participation and citizenship	17.1%	120
Diverse living arrangements, e.g. living with friends, live-in caregivers, independent living, etc.	16.9%	118
Quality of the workforce	15.9%	111
Transition from secondary education	15.9%	111
Innovation in service delivery	15.7%	110
Streamlining of regulations, policies and procedures	14.6%	102
Personal health initiatives, e.g. smoking cessation, nutrition, etc.	13.7%	96
Behavioral health and crisis intervention	12.9%	90
Housing assistance, e.g. mortgage products, rent subsidies, etc.	12.7%	89
Cross-systems collaboration, e.g. with Mental Health, Education, etc.	11.7%	82
Electronic record keeping	11.6%	81
Transportation	11.6%	81
Other (please specify)	10.9%	76

Summary of Write-In Comments from the Five-Year Plan On-line Survey

Many respondents also wrote responses to an open-ended question asking "Is there anything else you would like to tell OPWDD about the planning of services?" An analysis of these responses follows below.

Access

A primary concern was the maintenance of existing services and the opportunity for new support options, ranging from the development of supervised group homes to expanded access to self-directed supports through Consolidated Supports and Services (CSS). Respondents indicated a desire for enhanced access to services for an array of groups, including individuals with Autism Spectrum Disorder (ASD) and average intelligence, those with learning disabilities, medically frail adults and children, and those who enter the system at a later age. Some respondents voiced concern over wait lists and the approvals process, which many suggested could be accelerated. Especially concerned were aging parents who had been caring for their (now adult) children and now seek out-of-home residential supports. Simplified access to medical services and community activities were requested. Other related comments included the desire for increased eligibility assistance, continuing to offer services for an unlimited time per individual needs, and the provision of local and centralized services.

Service Coordination

Service coordination was another prominent theme; respondents stressed its importance to people of both higher and lower support needs. For the former, service coordination also provides advocacy and safeguards. For the latter, it was suggested service coordination can allow these individuals to live with the minimum level of supports (and maximal level of independence).

Some concerns were raised with regard to the redesign of Medicaid Service Coordination (MSC,) including the possibility it could lead to reduced access to services. Service coordinators perform a critical function, and one opinion was that Medicaid Service Coordinators need to focus solely on the coordination of services as per the MSC agreement. It was furthermore noted that support workers could perform some functions of service coordinators. Service coordinators for young adults in transition were also suggested.

There's Something About Monroe… The average county accounts for 1.61% of responses to the online survey. Above average then is Monroe County, which provided 8.5% of all surveys. The "runner-up" for most responses submitted was Erie County with 6.5%, followed closely by Suffolk at 6.3.

Special Populations (autism, aging, children and dual diagnosis)

Nearly as many comments were received about the development of services for individuals in what are referred to as "special populations" as were received related to service access and coordination. A primary area of response related to supports for individuals with autism and Autism Spectrum Disorder (ASD). The development of supportive and supervised residential and day options for those with ASD was requested. Additional concerns included access to innovative therapies for autism, promotion of autism awareness, and supports and service coordination for individuals with autism who are aging.

A focus on aging services was also evident, as the needs of the aging population were reiterated in a number of comments. A concern noted by several respondents was the transition of older individuals from day

programs into retirement with appropriate care and activities; integrated senior center opportunities were suggested. Also requested were enhanced planning for the aging including barrier-free residences, medical needs accommodation and services for older individuals with dementia.

In contrast, concerns and suggestions related to supports for children and adolescents were also voiced. These included development of supports for young adults with average IQ but who need to develop social and employment skills, and residential placements for medically frail children. Some parents expressed the hardships they have experienced caring for their children at home and the need for additional support. One suggestion was for the development of an initiative for children with developmental disabilities to include "direct services (e.g., screening and evaluation), indirect services (e.g., family support) and realistic cross-systems collaboration."

Another focus of comments was support for individuals who have both a developmental disability and a mental health diagnosis (i.e., dually-diagnosed.) A desire for expanded life, social, and employment skills for the dually-diagnosed was noted. Services and residences for individuals with high medical needs and substantial physical disabilities were also requested by some respondents.

Family Supports

Most comments related to family support involved access to respite for a wide variety of groups, including children with behavioral needs and others with high needs. Access to both in-home and out-of-home respite were noted as concerns. Many other comments related to the importance of at-home residential habilitation, with some expressing concerns over the number of providers offering the service. The importance of family counseling was also noted.

General comments related to family support included a call for expanded access, including the allocation of additional units of service. Some respondents noted the importance of non-waiver family supports, including special recreation.

Quality of the Workforce

The majority of comments in this area focused on direct support professionals (DSPs). These comments included enhancing pay and benefits for DSPs; training and developing DSPs; and ensuring DSPs are qualified, perhaps through a credential. Family members also expressed satisfaction with the DSPs who are caring for and supporting their loved ones. Some comments were related to the background check process, with a suggestion that a psychological profile also be conducted in addition to the criminal background check/fingerprinting process. An increase in pay for MSCs and skilled nurses was also suggested, as was finding ways to sustain employee morale.

Baby Boomers, the Traditionalists, and Generation X… People from these generational groups constitute the bulk of respondents to the online survey. Persons aged 31-50 accounted for 46.3% of responses, and those over 50 for 45.3%. "Millennials" (aged 18-30) accounted for 8.2% of the response.

Streamlining Regulations, Policies and Procedures

Comments relating to streamlining referred to reducing regulations, paperwork, and other rules seen by some as negatively impacting person-centered planning and inclusion. The reduction of regulatory requirements was suggested as a way to allow a more direct focus on the individual. Other comments related to the duplication of effort and paperwork in some processes. "Getting OMIG (the Office of the Medicaid Inspector General) and OIG (the Office of the Inspector General) on the same page to reduce the number of audits" was also suggested.

Transition from Secondary Education

Many comments were received with a focus on the transition of students with developmental disabilities from secondary special education to the adult service system. A major point of concern was the transition from school to meaningful college and work opportunities. Suggestions included working with high schools to plan transition and the addition of transition-specific service coordinators. Other areas mentioned include the development of assisted living and group homes for young adults with developmental disabilities, as well as the importance of maintaining consistent medical supports throughout the transition process.

Individual Control of Supports and Services

Comments referring to individual control over supports and services focused mainly on the movement toward a more individualized system in housing, day and other supports. Building an infrastructure to support person-centered services and continuing the shift from a "provider based to person/family based system" were also recommended by respondents. A want for broader flexibility and expanded access to self-determination/CSS were expressed, as were several comments in support of portable budgets whereby the money "follows the individual" regardless of where they receive services. Enhancing flexibility for independent living was also suggested by some respondents.

> **"Nothing About Us Without Us!"…** "Label Jars Not People!"…"Don't Think We Don't Think!"… These are great historical self-advocacy slogans and OPWDD is proud to note that 46.4% of respondents selected Self-Advocacy as an area where OPWDD has accomplished the most over the past year—the most-selected response!

Personalized Supports and Services

Many comments were received regarding personalized supports. Personalized supports and services are different from individually-controlled services in that these options do not necessarily reflect that the individual is engaged in self-direction. The priority is providing the individual appropriate support based on the needs of the individual and family. It was expressed that choice should be available to all people, forgoing one-size-fits-all services in favor of planning based on individual choice and ability. It was also noted that OPWDD serves a very culturally diverse population, making personalization all the more important.

Group Homes

A number of comments called for the construction of new supervised group homes for the general developmental disability population as well as groups such as adults with autism, medically frail children and those with intense needs. Other comments called for better coordination of medical care between group homes and parents, that group homes should be less restrictive and that group homes should be more greatly regulated.

Employment and Community Volunteer Work

"Critical" and "vital" were two words used to describe the importance of employment and volunteer work. It was noted that people with developmental disabilities want to work for pay, and without jeopardizing their (service) benefits. Some suggestions included the expanded use of supervised work enclaves and mentor or apprentice programs. Additional creative volunteer opportunities were requested by some respondents.

- Comments related to **public information and outreach** included continuing communication with families, public relations on the use of person-centered language, raising autism awareness, and conducting outreach related to setting up community-based activities.
- **Cross-systems collaboration** was encouraged through many comments to prevent the issuance of mixed messages from different systems, simplify advocacy, and ensure access to services for individuals diagnosed with both a developmental disability and mental illness.
- **Housing assistance** was suggested in the form of rent subsidies and working with HUD to offer "IRAs that could be staffed by agencies but without the cost of having to purchase property."
- Several respondents noted that **innovative approaches to service delivery** through the creation of new supports may also lead to the ability to provide services to more people. Looking at other states to find innovative options and ensuring consistency between policy and implementation were both recommended.
- A need for enhanced access to **transportation** was noted, including transportation in rural areas, for the medically frail, and for individuals who are not Medicaid eligible.
- **Day services in group settings** received some support, with requests for meaningful day habilitation for students transitioning from schools and higher functioning individuals.
- Increased accountability through **quality management and performance accountability** was suggested, as was the outside review of complaints.
- **Community attitudes and acceptance** for individuals with developmental disabilities living in communities, and in the workforce, were noted as priorities to ensure "respect for all people."
- The importance of helping people form **relationships** in avoiding loneliness through community involvement was also stressed.

Appendix B

Comparison of NCI - Consumer Survey Results Over a Two Year Period

The following report summarizes results from OPWDD's National Core Indicators (NCI) data collection effort giving special attention to our "People First" goals: home, health, relationships, and jobs/productivity. In addition to these core areas, OPWDD will also analyze indicators of choice and individualization of services. Results from the NCI project are used to inform OPWDD's leadership team about the strengths and weaknesses of our system and provide an empirical basis for strategic planning.

By participating in the NCI process on an annual basis, OPWDD 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 database, provides a report comparing the performance of New York with other participating states. HSRI's reports on the NCI initiative can be accessed by following links from their home page (http://www.hsri.org/).

NCI is becoming an integral part of developmental disability quality management systems around the country as over half the states in the nation now participate. OPWDD's larger goal is to better monitor our support of people with developmental disabilities and their families. The NCI Consumer Survey is part of an ongoing dialogue between OPWDD and the people OPWDD serves to determine what works and what needs to be modified in charting a course for the future. Another aim of this endeavor is to make the NCI data part of a metrics-based quality management system gauging the extent to which OPWDD's services enhance the quality of life of the people served. The survey results will help create an action plan to improve the quality of life for all people with developmental disabilities in NYS.

Methodology

Each 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. The New York sample was stratified across DDSO regions and also by the core services provided by OPWDD. The data for 2007-08 were stratified according to residential, day and individualized services while the 2008-9 data were stratified by residential, day, family support, and individualized services/Consolidated Supports and Services. The stratification ensured that the sample accurately reflected the population of individuals receiving OPWDD services. The sample for 2007-08 included 464 individuals receiving traditional services and 246 individuals receiving services through Options For People Through Services (OPTS). In 2008-09 the sample was greatly increased in order to allow greater group comparisons across regions and programs. The sample used to represent NYS included 1502 people.

Data Collection

A variety of individuals served as NCI interviewers. They were trained by a combination of HSRI employees, Central Office staff and NCI DDSO liaisons responsible for implementing regional data collection activities. The purpose of the training was to teach interviewing skills and standardize the way in which NCI survey questions were asked. In both years, the Division of Quality Management staff interviewed people in certified residences while the DDSO staff interviewed those receiving family care, developmental center, day, family support, and individualized services.

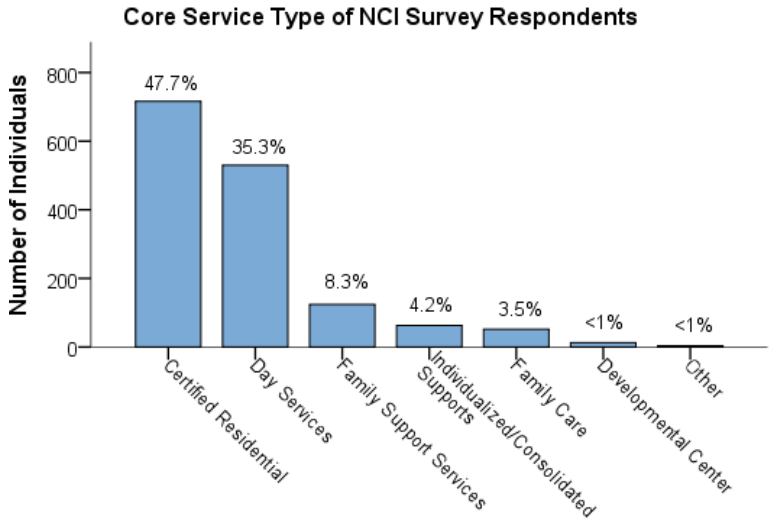
Sample Characteristics

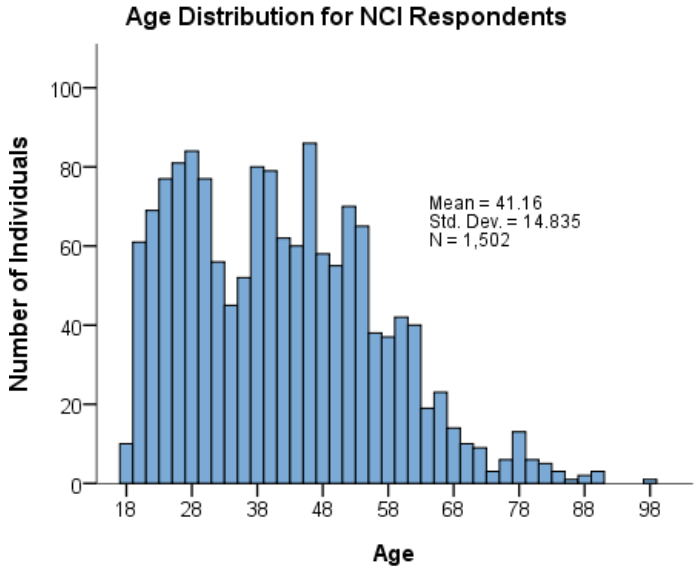
The four graphs that follow describe the various characteristics of the individuals who were interviewed during the 2008-09 data collection cycle.

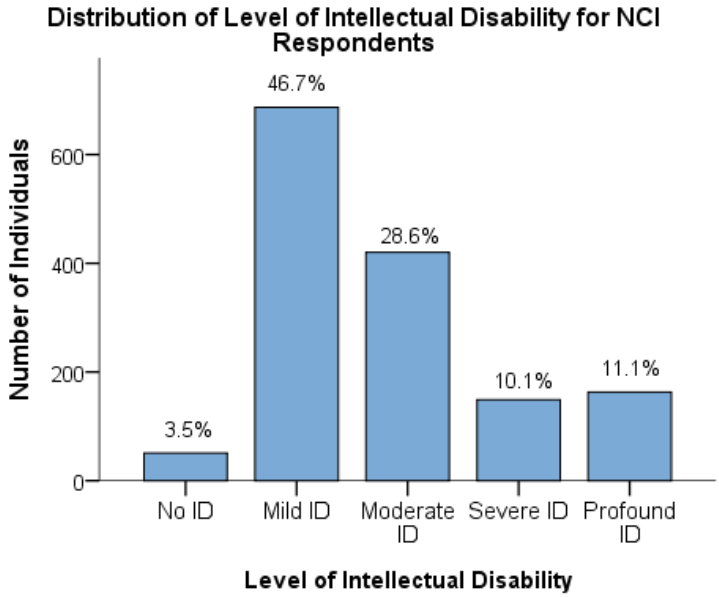
The first graph shows the breakdown of respondents by their core service. The vast majority of NCI survey respondents have residential services or day services. Individuals with both types of services were counted in the residential services category.

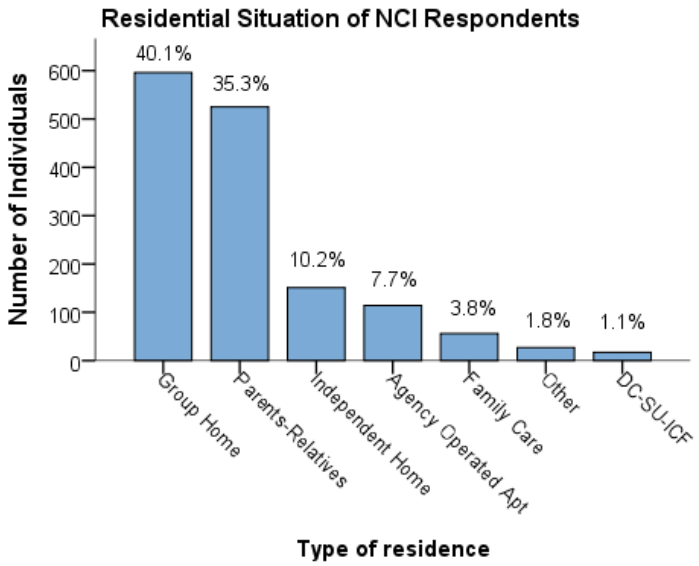
The second graph shows that the age distribution of the individuals participating in the NCI survey (keep in mind that the survey only includes people 18 and over). The sample mean age of 41 is representative of the population served by OPWDD. This is an improvement over the 2007-08 data, which yielded a mean age that was slightly older than the population.

The third graph portrays the intellectual functioning levels among respondents. About half of the respondents were people with a mild intellectual disability or no intellectual disability. The other half of the respondents had a moderate, severe or profound intellectual disability. The NCI protocol includes a section of the form where people who need accommodation can answer with the assistance of caregivers or by proxy so that people of all disability levels are represented in the survey process.









The fourth graph describes the living situation of survey respondents; a full range of residential possibilities is depicted. By far, the most common living arrangements are living in a group home or living with family members (just over three-quarters).

Results

The following tables examine how OPWDD is faring in relation to its core values. For each of the content areas that follow (home, relationships, health, productivity, choice, and individualization) respondents were asked questions with responses of 'yes/sometimes/no' or 'never/once in a while/usually/always'. Unless otherwise noted, most of the tables report the percentage of people who replied "yes" to the survey item. The results from the 2007-8 and 2008-09 surveys are both reported. Please note that some of the 2008-09 survey items have been worded differently than the previous survey. Revised items have a double asterisk (**) on the left-hand side of the tables below.

Table 1 shows that the majority of respondents are positive about many aspects of their home life. Note that the data seems fairly stable between the two survey periods with the new data falling within +/- 5 percentage points of the previous year.

All numbers are percentages (%)

Indicators of Satisfaction with HOME LIFE

Table 1.

	Yes	
	NYS '07-'08	NYS '08-'09
Is your home staff nice and polite to you?	93	96
Do you like where you live?	92	90
Do you feel safe in your home?	82	83
Do you feel safe in your neighborhood?	80	85
Do people enter your bedroom without permission?	20	17

Table 2 shows that, while most people have friends and family that they feel close to and interact with, there are still many individuals who are lacking quality relationships. Most people should have a companion that they feel close to and friends that they talk to and do things with. A sizeable proportion of respondents felt that they were not always able to see friends and family when they would like to, suggesting that there may be some barriers to access.

Indicators of QUALITY RELATIONSHIPS

Table 2.

	Yes	
	NYS '07-'08	NYS '08-'09
Do you have a best friend or someone you are really close to?	85	77
Can you see your friends when you want to see them?	77	79
Can you see your family when you want to?	75	83
Do you have friends you like to talk to or do things with?	74	76
Do you ever feel lonely?	38	37

Table 3 presents outcomes on health indicators. The vast majority of people (over 90%) receive a routine physical but ancillary medical services are not always utilized with the frequency recommended by health care practitioners. Please note that two of the health questions reported on here were reworded for the 2008-09 survey. The 2008-09 survey asked specifically about receiving a pap test in the past year as opposed to a gynecological exam. The survey item about physical activity has also changed to "does this person routinely engage in any moderate physical activity?" from "how physically active is this person?" The percent reported for '08-'09 reflects the percentage of people *who engage in moderate physical activity for at least 30 minutes three times a week,* thereby the first column recounts a negative health assessment and the second a positive.

Indicators of HEALTH

Table 3.

	Yes	
	NYS '07-08	NYS '08-'09
Received a routine physical exam in the last year?	92	91
Received a gynecological exam in the last year?** (08-09 survey result reflects % receiving Pap test)	58	64
Received a dental exam in the last six months?	62	67
Does this person smoke or chew tobacco?	5	7
Is this person physically inactive?** (08-09 survey result reflects the % who are **active**)	28	56

Table 4 demonstrates that most people enjoy their participation in daytime activities. Interactions with day staff are characterized as respectful. Opinions are not as highly positive for other survey items that address work or day activities. Many individuals reported that they would like the opportunity to work more hours and earn money. Those who were judged to be around retirement age were asked whether they could stop going to day services and a sizeable portion reported that they did not have this option.

Indicators of PRODUCTIVITY/DAYTIME ACTIVITIES

Table 4.

	Yes	
	NYS '07-'08	NYS '08-'09
Do you like your job or day activity?** (08-09 has separate items for those who work)	95	91/88 (job/day activity)
Is the staff at your day program/work nice and polite to you?** (08-09 has separate items for those who work)	94	96/96 (job/day activity)
Do you work as many hours as you want?	69	64
Do you have a chance to earn good money?	72	72
Can you retire?	68	57

Performance on items related to choice was mixed. The majority of respondents reported that they are empowered to choose everyday activities such as what to do during free time and deciding their daily schedules. However, major decisions, such as where and with whom a person lives were made only by a minority of the respondents. Less than half of respondents had any input at all into these decisions. The percentage of respondents with positive responses did not show much change between survey periods with the exception of two items. A greater percentage of respondents reported having input in choosing who helps them at home. Also of note is that HSRI asked about choice of work place and choice of day activity in two separate questions in the 2008-09 survey as opposed to combining day and work activities into one question as in the year before. The results for the 2008-09 data show that people who work have more choice about where they work, whereas respondents in day activities experienced less choice about where they go.

Indicators of CHOICE

Table 5.

	Person Chose/Had Input	
	NYS '07-'08	**NYS '08-'09**
At your home, do staff work the hours that best meet your needs?	90	91
Does the staff at your home do things the way you would like?	76	83
Does the staff at your home know about your goals and needs?	92	89

Overall, NYS performed well in delivery of individualized services. More indicators are necessary to truly measure this concept, but existing indicators are positive. All of the questions below were added to the NCI consumer survey by NYS OPWDD.

Indicators of INDIVIDUALIZED SERVICES

Table 6.

	Person Chose/Had Input	
	NYS '07-'08	**NYS '08-'09**
Who chose the place where you live?	48	40
Did you choose the people you live with (or to live by yourself?)	27	35
Did you choose who helps you at home?	59	68
Who decides your daily schedule?	70	77
Who decides how you spend your free time?	87	88
Who chose the place where you work/go during the day?** (08-09 has separate items for those who work)	54	76 (work) 59 (day)

Appendix C

Summary from 2011 County Plans

The *2011 Local Services Plan Guidelines* represent the third year of interagency collaboration among all three NYS Mental Hygiene Agencies: the Office of Alcoholism and Substance Abuse Services (OASAS), the Office of Mental Health (OMH), and the Office for People with Developmental Disabilities (OPWDD). The web-based County Planning System (CPS) is an efficient and cost-saving application that benefits stakeholders who participate in the planning process. 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.

CPS 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. This integrated planning process enhances the abilities of the counties to address cross-system issues that impact individuals with co-occurring disorders. In addition, the data analysis capabilities in CPS allow state agencies to assess the most pressing needs across the state.

Priority Outcomes and Strategy 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 well-being. A *system* focus results in a desirable, measurable outcome for the service system.

Most Priority Outcomes refer to at least one strategy to accomplish activities defined in the Priority Outcome. A strategy is a specific measurable statement about what change needs to occur in order to achieve the stated outcome. Counties then choose at least one focus area to summarize the intent of each strategy.

Table 1 identifies the frequency with which each Strategy Focus Area is identified as part of a Priority Outcome related to OPWDD and the other mental hygiene agencies. Counties identified Cross Systems Collaboration (113) as the most frequent focus area for all three agencies. The next numerous focus areas were Service Access (Capacity) (54), Workforce Development (29), Quality Management (27), and Housing (25). Only one focus area pertained to OASAS and OPWDD, however results for OMH and OPWDD suggest more integration between these two service delivery systems. Again, Cross System Collaboration was chosen as the most frequent focus area for OMH and OPWDD (42), with Service Access (Capacity) as next most numerous (30).

Table 1. Strategy Focus Areas

	OPWDD	OASAS & OPWDD	OMH & OPWDD	All 3 Agencies
Cross System Collaboration	35	1	42	113
Service Access (Capacity)	72	0	30	54
Mental Hygiene Workforce Development	25	0	8	29
Quality Management	3	1	3	27
Housing	53	0	7	25
Service Engagement	11	0	9	23
Social Connectedness / Inclusion / Social Support	44	0	9	20
Transportation	15	0	1	16
Employment / Education	31	0	12	14
Health & Wellness	13	0	4	13
Self-Direction	22	0	7	12
Other	21	1	4	12

The information in Table 1 was then reviewed to determine which Strategy Focus Areas were identified most frequently by the Counties as areas of need. The data from the first column of Table 1, which identifies the strategy focus areas for OPWDD, was used for the analysis in Table 2. Percentages were determined using the total number of Priority Outcomes identified as "**OPWDD Only**".

Table 2. Most Frequently Identified Strategy Focus Areas

Strategy Focus Area	Percent
Service Access (Capacity)	20.9%
Housing	15.4%
Social Connectedness / Inclusion / Social Support	12.8%
Cross System Collaboration	10.1%
Employment / Education	9.0%
Mental Hygiene Workforce Development	7.2%
Self-Direction	6.4%
Other	6.1%
Transportation	4.3%
Health & Wellness	3.8%
Service Engagement	3.2%
Quality Management	0.9%

Table 2 indicates that the top five areas identified were Service Access (Capacity,) Housing, Social Connectedness/Inclusion/Social Support, Cross Systems Collaboration, and Employment/Education.

While many priorities are shared throughout the state, planning at the county level leads to a diverse range of local priorities. Expanding access to services and cross-system collaboration to ensure consistent support are the top priorities statewide and the top priorities of virtually all DDSOs and New York City, which conducts its mental hygiene planning as a single entity. The tables on the next page show the top five Priority Outcomes identified by DDSO region or New York City. Outside of Cross System Collaboration and Service Access

(Capacity), the areas most frequently targeted as priorities (not including "Other") are Housing, Service Engagement, Health and Wellness, Social Connectedness / Inclusion / Social Support, Workforce Development and Quality Management, in that order.

The Focus of Top Priority Outcomes, DDSOs and New York City

BROOME	
Service Access (Capacity)	21.7%
Cross System Collaboration	19.6%
Quality Management	11.3%
Service Engagement	10.4%
Housing	8.7%

LONG ISLAND	
Housing	19.5%
Cross System Collaboration	17.1%
Service Access (Capacity)	14.6%
Workforce Development	14.6%
Health & Wellness	7.3%

CAPITAL DISTRICT	
Service Access (Capacity)	22.4%
Cross System Collaboration	15.6%
Social Connectedness/Inclusion	11.9%
Housing	9.8%
Health & Wellness	7.5%

NEW YORK CITY	
Service Access (Capacity)	20.4%
Cross System Collaboration	13.9%
Other	10.2%
Housing	9.3%
Social Connectedness/Inclusion	9.3%

CENTRAL	
Service Access (Capacity)	18.6%
Cross System Collaboration	18.6%
Housing	10.3%
Other	9.0%
Social Connectedness/Inclusion	7.4%

SUNMOUNT	
Service Access (Capacity)	24.3%
Cross System Collaboration	19.7%
Service Engagement	8.6%
Health & Wellness	7.2%
Other	7.2%

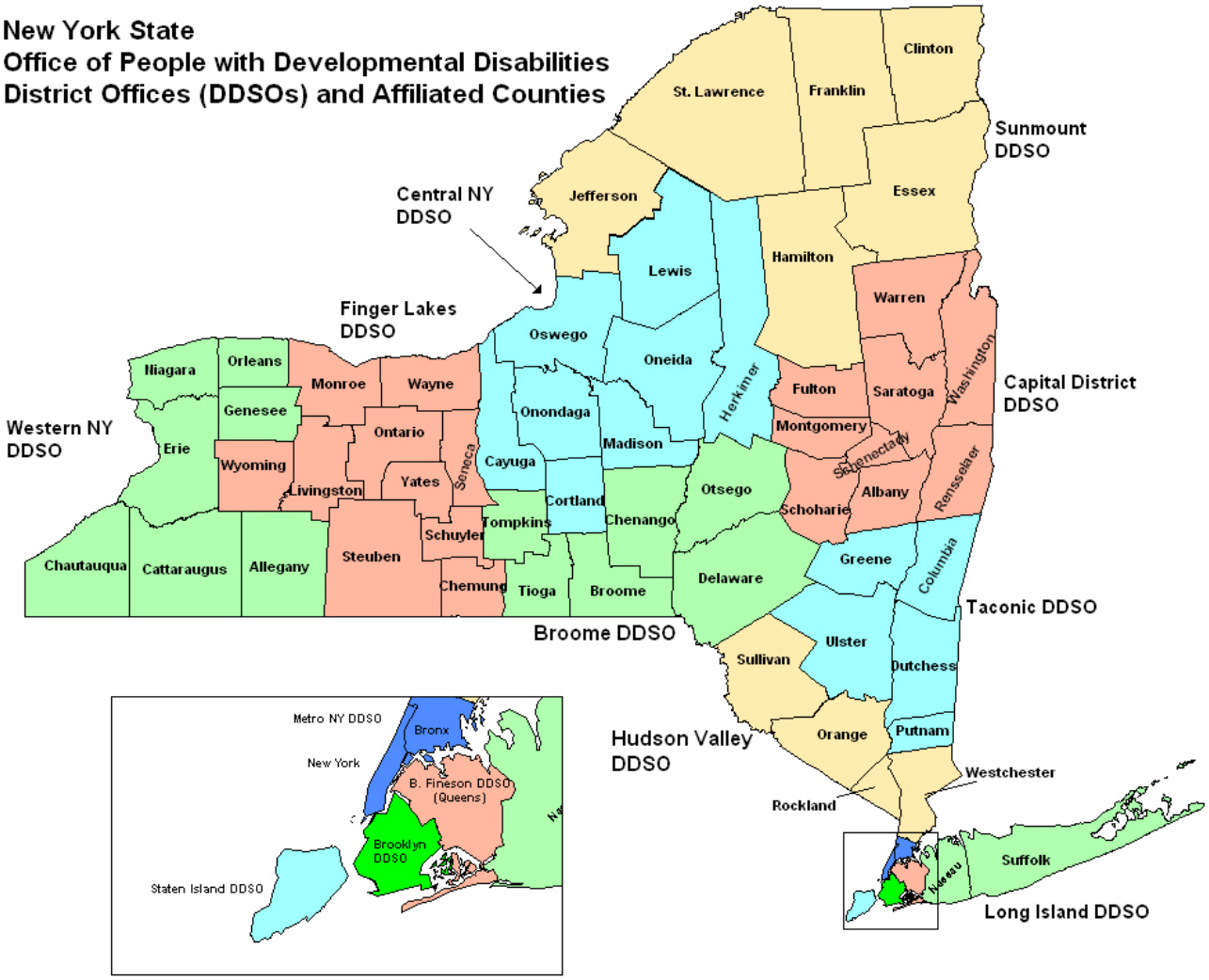
FINGER LAKES	
Cross System Collaboration	20.5%
Service Access (Capacity)	16.1%
Health & Wellness	9.8%
Service Engagement	9.4%
Housing	7.9%

TACONIC	
Service Access (Capacity)	25.2%
Cross System Collaboration	18.6%
Service Engagement	12.8%
Health & Wellness	10.7%
Housing	8.3%

HUDSON VALLEY	
Cross System Collaboration	21.6%
Service Access (Capacity)	21.0%
Housing	8.7%
Workforce Development	8.7%
Service Engagement	7.8%

WESTERN	
Service Access (Capacity)	21.5%
Cross System Collaboration	18.2%
Service Engagement	13.2%
Quality Management	9.1%
Social Connectedness/Inclusion	7.9%

Appendix D


New York State
Office of People with Developmental Disabilities
District Offices (DDSOs) and Affiliated Counties
Central NY DDSO
Finger Lakes DDSO
Western NY DDSO
Sunmount DDSO
Capital District DDSO
Taconic DDSO
Broome DDSO
Hudson Valley DDSO
Long Island DDSO
St. Lawrence
Franklin
Clinton
Jefferson
Essex
Lewis
Hamilton
Warren
Oswego
Oneida
Herkimer
Fulton
Saratoga
Washington
Niagara
Orleans
Monroe
Wayne
Genesee
Onondaga
Montgomery
Schenectady
Ontario
Madison
Erie
Wyoming
Seneca
Cayuga
Yates
Livingston
Otsego
Albany
Rensselaer
Schoharie
Cortland
Tompkins
Chenango
Schuyler
Greene
Columbia
Chautauqua
Cattaraugus
Allegany
Steuben
Chemung
Tioga
Broome
Delaware
Ulster
Sullivan
Dutchess
Orange
Putnam
Westchester
Rockland
Suffolk
Nassau
Metro NY DDSO
Bronx
New York
B. Fineson DDSO (Queens)
Brooklyn DDSO
Staten Island DDSO