

**PEOPLE FIRST**

1115 DEMONSTRATION WAIVER



Office for People With Developmental Disabilities

# Briefing Book

June 9, 2011



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## Introduction

This *Briefing Book* is meant to provide an overview of the NYS Office for People with Developmental Disabilities (OPWDD) to participants in the People First 1115 Waiver Steering Committee and Waiver Design Teams. The book is set up to provide an overview of the people served, available services within the system and the funding mechanisms in place at this time. Additionally, the issue of quality is discussed from both a baseline program expectation and from an oversight perspective.

The following topic areas are included in the book and align with the design teams that will explore the challenges identified in each section as the People First Waiver is developed.

1. People Served by OPWDD
2. Services and Benefits
3. Care Coordination
4. Financial Sustainability
5. Access and Choice
6. Quality

The data that was utilized to pull together some of the charts within the book come from a variety of sources and from various points in time. As a result, there is variation across some of the charts and within some of the text. At the time of the formal waiver application submission, the data will be more refined and reflective of current information and demographics.

As the system of care is strategically redesigned using the People First Waiver to support the meaningful outcomes of personal health and safety, positive relationships, work and meaningful activities and access to a desired home setting, the guiding principles of respect for individuals and families, effective care coordination, and realigned financial incentives will be at the core of the planning process.

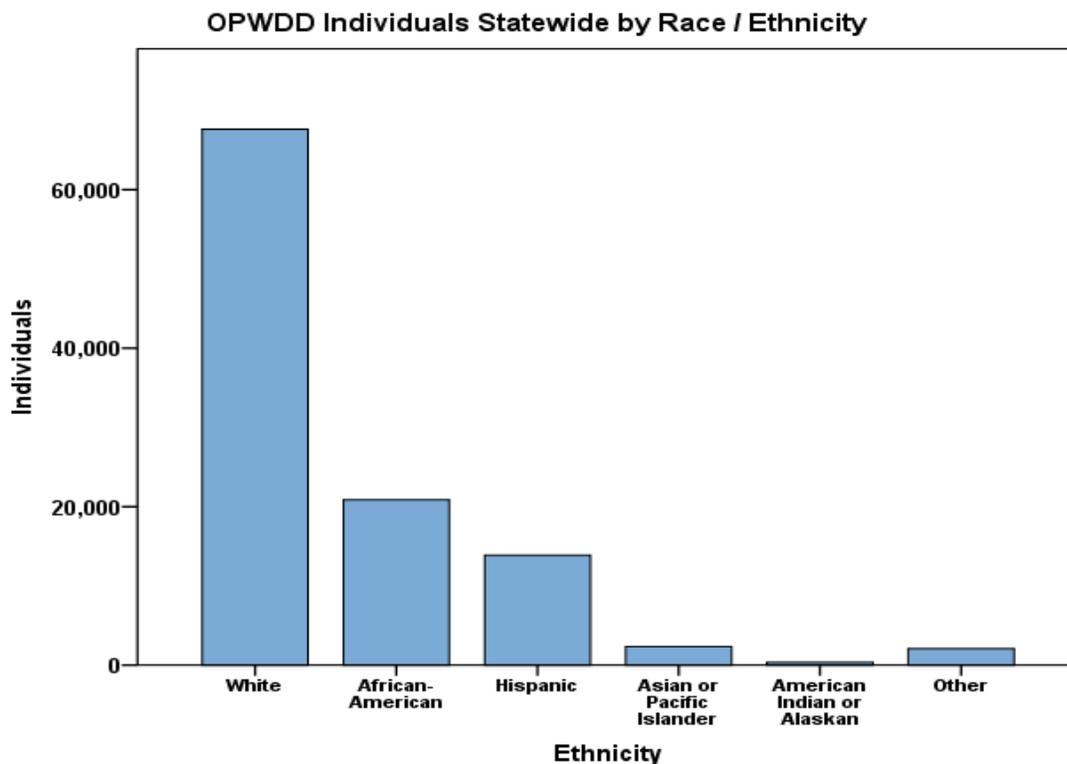
# People Served By OPWDD

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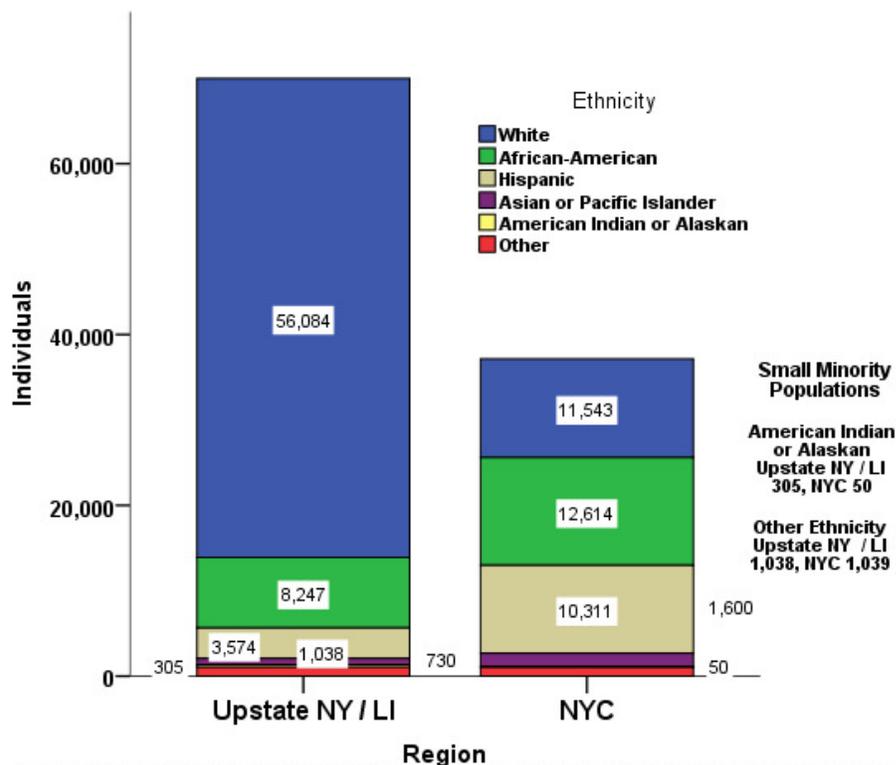
OPWDD supports a varied and growing group of families and individuals. This section provides a snapshot of the people served by Race/Ethnicity; Age Distribution; and Disability Description.

## Race/Ethnicity

As shown in the graph, *OPWDD Individuals Statewide by Race/Ethnicity*, OPWDD serves a diverse array of ethnic groups and must therefore address the cultural differences found in a state as large as New York. Overall, the diversity of the people served by OPWDD is roughly congruent with the state's general population. Furthermore, the proportion of people of color served has been steadily rising, increasing by over 10% in the last decade as OPWDD reaches out to New Yorkers of all cultures and communities. The second ethnicity graph, *OPWDD Individuals by Ethnic Group and Region*, details the racial breakdowns for New York City as compared to the rest of the state.



## OPWDD Individuals by Ethnic Group and Region \*

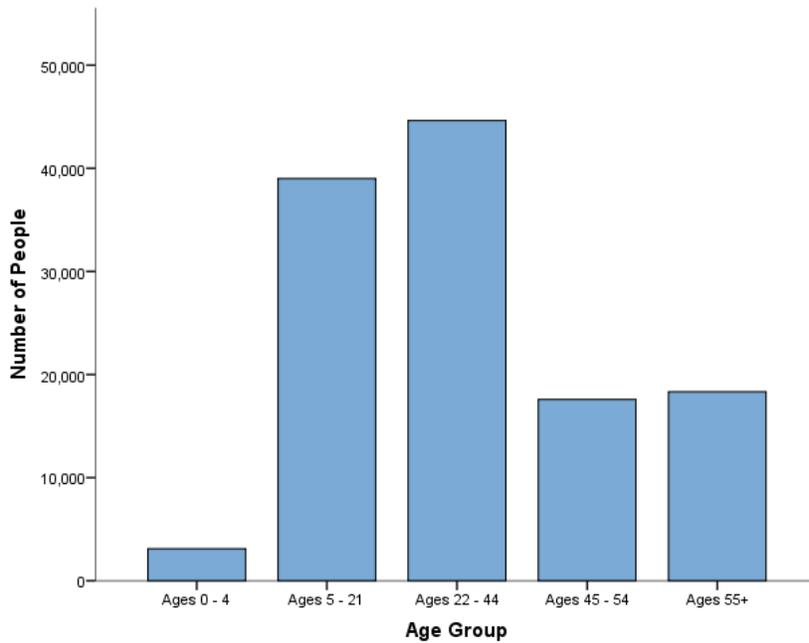


\* There are no listed ethnic groups for 15,530 people, which is 12.7% of the 122,655 people in this extract. Of these, 10,468 live Upstate NY / LI and 4,762 live in NYC.

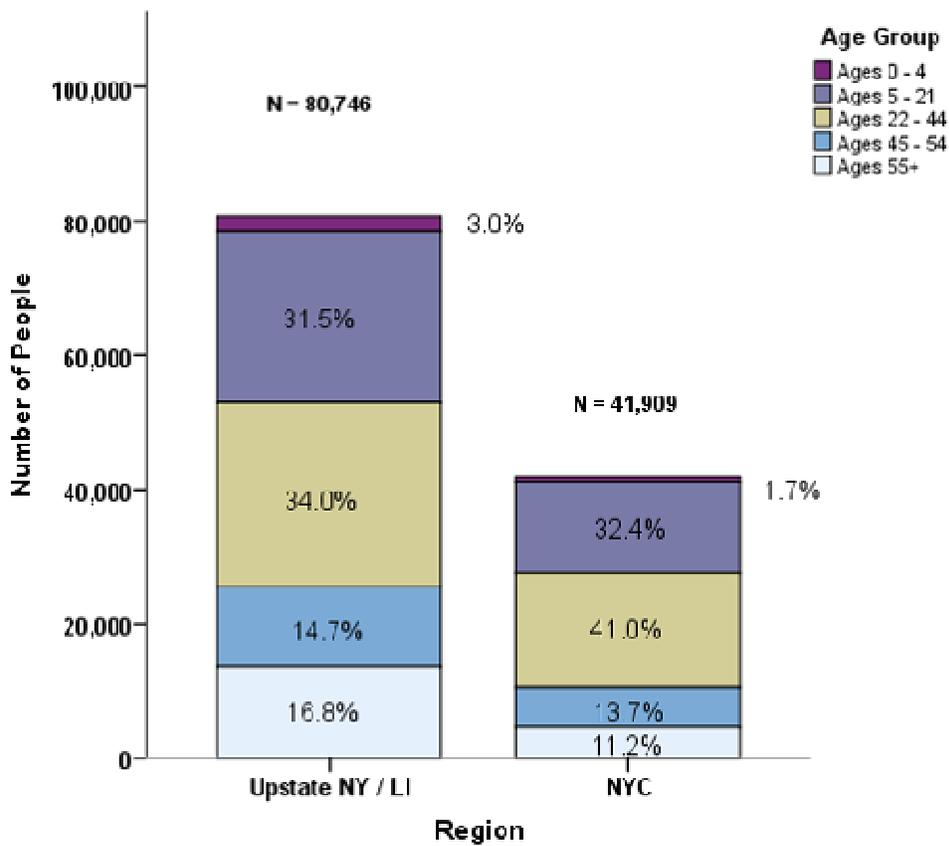
## Age Distribution

As shown by the following graph, *Statewide Age Distribution of People Receiving OPWDD Services*, our age range of individuals served 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 recent years. 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. An additional graph reflects the age of people served across the Upstate/Long Island and New York City regions.

Statewide Age Distribution of People Receiving OPWDD Services

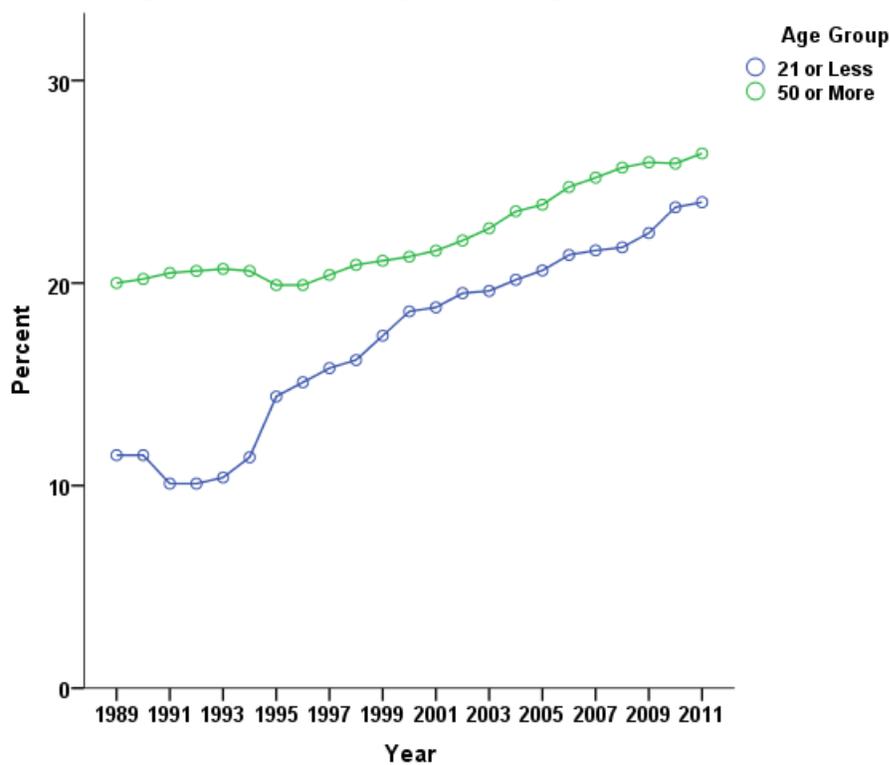


Age Distribution by Region



The graph below, *Historical Trends for Older/Younger Subgroups*, shows the trend for older and younger individuals receiving services and supports from OPWDD. These two age groups grew throughout the past 20 years and together represent nearly 50 percent of the total population of individuals participating in day and residential services. This upward trend suggests an increasing need for supports designed for children and transition age youth, including family support services, community habilitation and supported employment. Similar to the general population, individuals with developmental disabilities are living longer and therefore require more assistance to age in place as they enter their 50s and beyond.

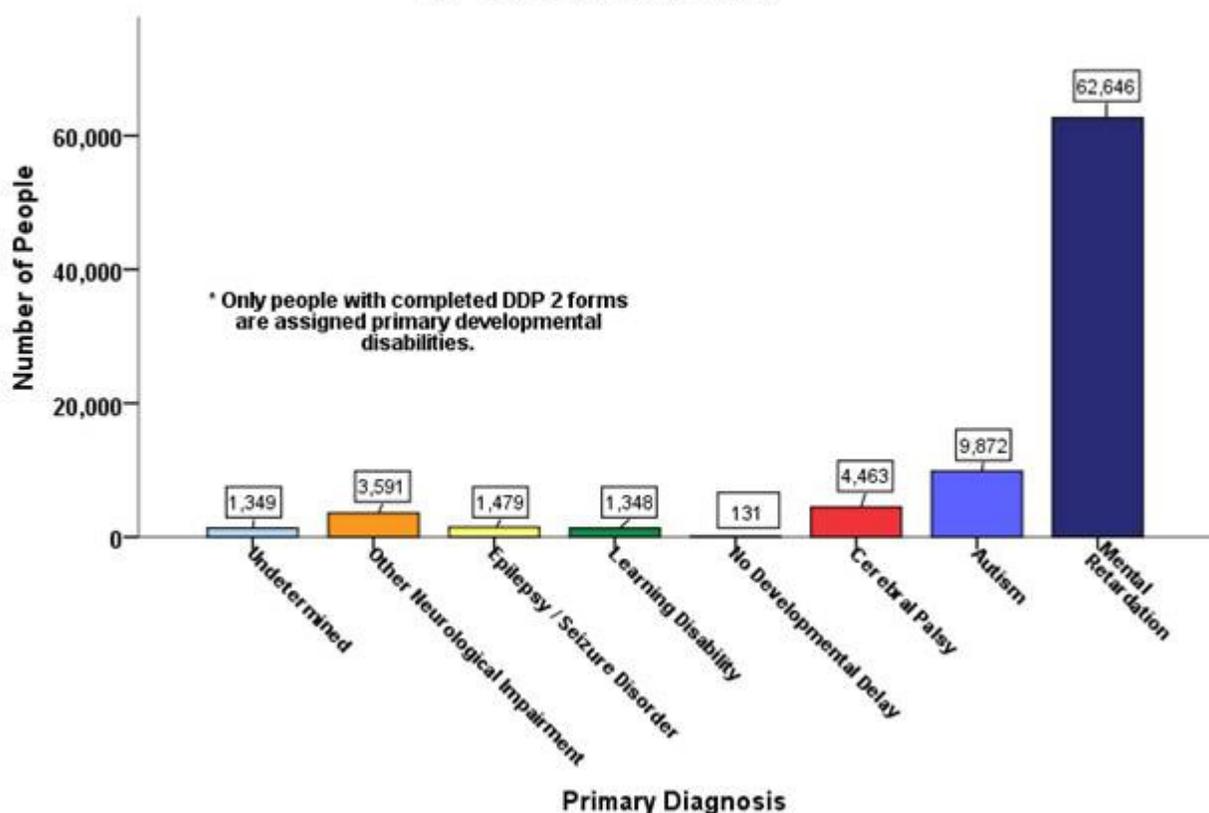
**Historical Trends for Older/Younger Subgroups**



## Disability Description

As shown in the following graph, *Primary Disability of People Served*, the vast majority (74.9%) of people receiving services are designated as having mental retardation as their primary disability. At just under 10 percent, autism is the second most common primary disability. These percentages represent all people who have a specified **primary** disability on record in our service system.

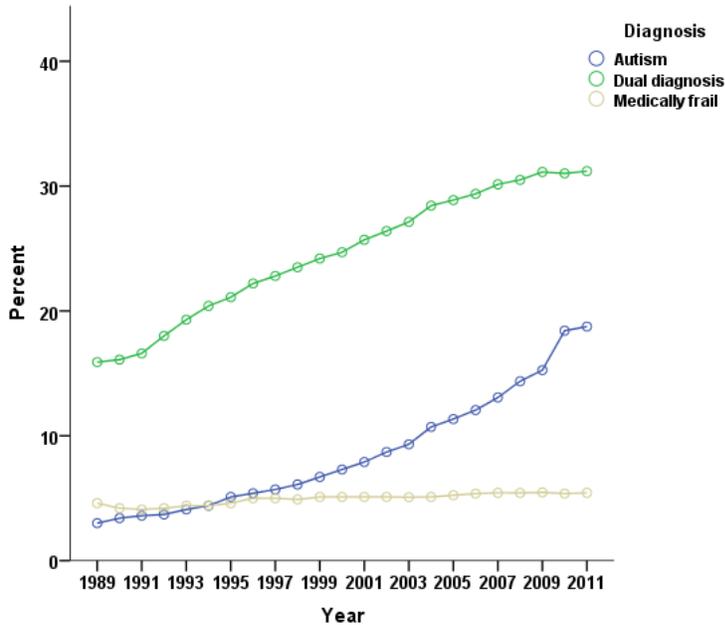
**Primary Disability of People Served**  
(N = 84,879, March, 2011 \*)



### Special Populations and Cross System Needs – Trends for Autism, Dual Diagnosis and Medical Frailty

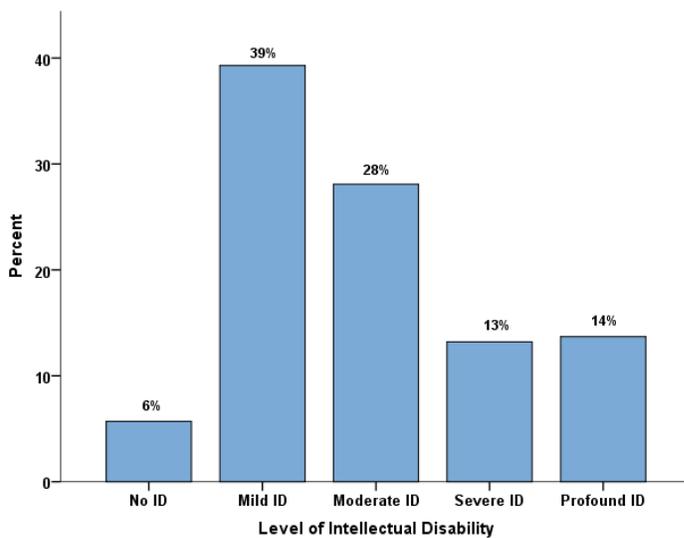
Historical trends show that the proportion of individuals from special population groups and those who have cross-systems needs is increasing. Over 30 percent of individuals in the OPWDD system have a psychiatric diagnosis that suggests service collaboration between both OPWDD and the New York State Office of Mental Health (OMH). As in other parts of the country, Autism Spectrum Disorder (ASD) is one of the fastest growing developmental disabilities in NYS. In fact, the proportion of people served with ASD has increased by nearly fivefold from only 3% in 1989 to more than 17% in 2010. Individuals who are medically frail are described as having multiple medical conditions which result in specialized diets, staff training in medical procedures, profound motor challenges, high self care needs, and absence from day program. Within the past 22 years this population has experienced only slow growth, but still reached the level of almost 5.5 percent of all individuals served.

## Historical Trends for Special Populations



The graph below portrays the statewide intellectual disability levels among people with developmental disabilities for 2011. Two-thirds of individuals fall into the mild or moderate functioning level. A smaller proportion of individuals do not actually have an intellectual disability (6%) but meet OPWDD eligibility criteria based on the diagnosis of other types of developmental disabilities.

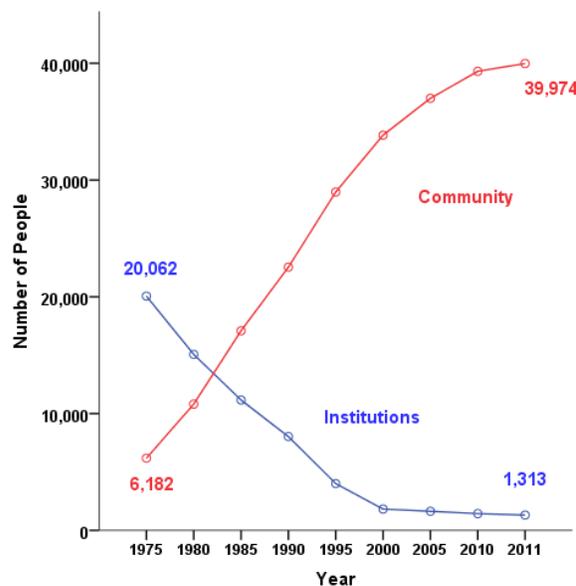
## Distribution of Intellectual Functioning Levels



# Services and Benefits

## Introduction

OPWDD is a young agency, born in 1978 following the legal battles fought on behalf of individuals living at the Willowbrook State School. We have traveled a long way in just 30 years. In the days of Willowbrook, families had two choices: institutionalization of their family member, or taking responsibility for lifelong care with little help and few service options. The Willowbrook litigation served as an impetus for change in the State, resulting in the closure of Willowbrook and other developmental centers and the creation of a system of community-based services and supports that have benefitted both the members of the Willowbrook class and other individuals with developmental disabilities in the State. In the past 35 years OPWDD significantly reduced the number of institutional placements and replaced it with a large, statewide network of community living options, including community residences and individually controlled residential supports.



As shown in the above graph, in the past 35 years OPWDD significantly reduced the number of institutional placements and replaced it with a large, statewide network of community living options, including community residences and individually controlled residential supports. The figure shows that the number of people served in community based services have grown over 500%, from 6,182 in 1975 to 39,974 by 2011. These opportunities were created to address the desire of people with developmental disabilities and their families for living arrangements in and outside of the family home. OPWDD is committed to maintaining a full array of residential support options to meet the needs of individuals, their families and advocates and moving the system forward toward more individualized service options.

This section offers a description of OPWDD's current services and the fiscal structure that supports the OPWDD system. In addition to the services described in this section, individuals served by OPWDD also receive service coordination (i.e., case management services) as part of residential services in Intermediate Care Facilities (ICFs) or through one of several vehicles: Medicaid Service Coordination (MSC), Plan of Care Support Services (PCSS) or for children who are enrolled in the Care at Home (CAH) waivers through CAH case management. Service coordination is described more fully in the Care Coordination section of this document.

In addition to the services described below, individuals with developmental disabilities who are Medicaid eligible may also receive services under the auspice of other state agencies (more detail in the Financial Sustainability section of this document). Through the People First Waiver, greater flexibility, transparency and efficiency in the delivery of appropriate supports will be pursued.

## **I. Community Services and Supports**

### **Family Support**

- Respite: both at family home and in free standing sites
- Recreation: at family home or in structured program
- Family member training
- Support groups
- Parent to parent networking
- Information and Referral
- Sibling services
- After school programs

### **Assistive technology and environmental modifications**

- Individuals receive access to technology that can support greater independence and learning opportunities to meet their needs.
- Individual homes or family homes are modified to meet the needs of an individual. Some examples include the addition of a ramp, a fence or other safety features.

### **Community Habilitation**

Habilitative supports provide individuals receiving services with opportunities to learn and experience community based activities. Learning is often focused in the areas of social skill building, activities of daily living skill development, behavior stabilization, and health education. Habilitative plans are developed based on a person's valued outcomes and specific goals are set to help the individual meet those valued outcomes.

### **Self directed supports**

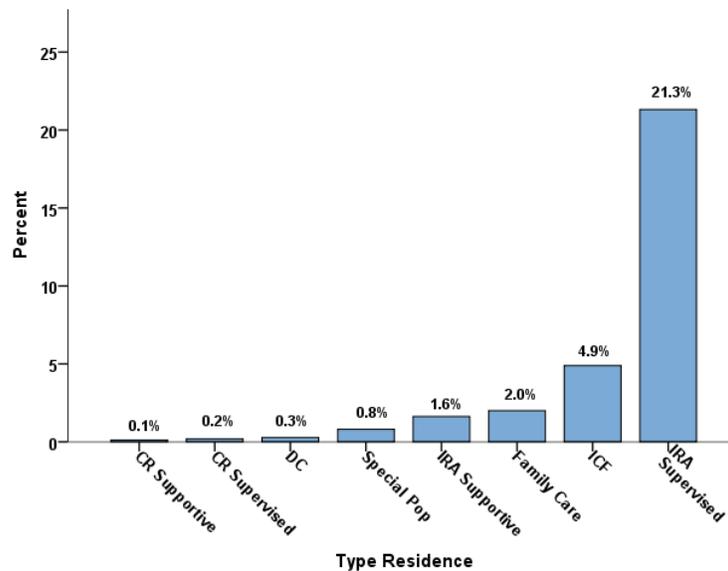
Individuals served by OPWDD along with their families are provided with options to obtain supports in an individualized manner. The option of Consolidated Supports and Services (CSS) allows individuals and/or their families to self hire staff to support their needs. There are monetary thresholds set within this service delivery option based on an individual's demonstrated need and justifications for resources based on those needs. Individuals or family members manage the resources allocated, often with the help of an agency intermediary and a service coordinator, as needed to meet their ongoing needs and interests. In addition to CSS, which is a HCBS waiver option, many individuals use Individual Support Services (ISS) which is a financial stipend that helps OPWDD eligible individuals manage their living expenses in an uncertified living environment – this is a financial support that is state paid.

### **Clinic Services**

OPWDD both operates and certifies Article 16 clinics for the provision of clinical services. Specifically, clinics can provide services including primary medical/dental, occupational therapy, physical therapy, psychology and/or psychiatry, rehabilitation counseling, speech and language pathology and/or audiology and social work. The clinics are established to meet the needs of individuals with developmental disabilities in areas where there is insufficient generic providers or for individuals with more complex needs related to their developmental disability.

### **Certified community residential settings**

The graph below represents the percentage of individuals currently living in residential programs. Approximately 31 percent of people receiving services from OPWDD reside in certified residential settings. Supervised homes are those that support people 24/7 and supportive settings provide less than 24/7 staffing. The majority of people who access OPWDD services continue to receive supports in their own home or the home of their family members. Overall, OPWDD hopes to provide a diverse array of living situations that appropriately match the needs and abilities of individuals in New York State.



### Individualized Residential Alternatives (IRA)

- An IRA is a certified setting that meets identified health and safety regulatory standards in which support services are delivered using residential habilitative waiver services. Each person's needs are defined within their individualized service plan (ISP). Based upon the persons identified needs additional plans of care are developed to guide responsible staff in the implementation of needed supports and treatment.
- IRAs vary significantly in size, location and individuals' needs; there is not one consistent IRA model as the supports provided are dependent on the identified needs of the individuals living there. IRAs are operated by both the State and voluntary providers.

### Family Care

- Family Care offers an option for individuals to live within a family environment and receive supports and services consistent with their defined needs. Family care homes are certified settings with defined environmental and provider requirements. Most typically, family care settings serve one or two individuals. Individuals' needs are defined within plans of care that are implemented by the family care provider.

### Community Intermediate Care Facilities (ICF)

- An ICF is operated under the federal part 483 regulatory requirements. Services delivered within the ICF are "bundled", meaning that all individuals must be assessed annually regarding their needs in each of the required clinical domains and plans must be developed to ensure that the individual is provided active treatment to address the identified needs.
- Approximately 5% of the individuals receiving OPWDD services live in a community ICF setting.

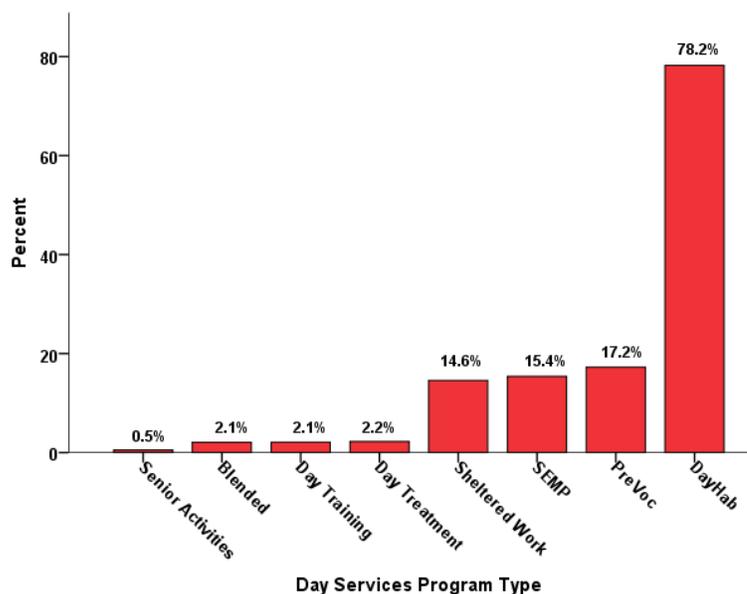
## Day Supports

Individuals with developmental disabilities participate in a variety of activities, programs and employment opportunities throughout their day. Some individuals receive daytime supports in their home (IRA) setting during the day due to their medical frailty or age. Some program options include:

- Day Habilitation: activities are provided at either a site-based location or directly in the community (without walls) which focus on skill building and meeting a person's valued outcomes.
- Pre-vocational Programs: focus on employment skill building. Individuals receive payment on a scale determined by their capacity to complete the tasks in question.
- Supported Work: individuals are provided with job coaches who assist them in obtaining and maintaining employment.
- Sheltered employment: individuals work in a setting predominantly with other individuals who have developmental disabilities. Many individuals in sheltered employment are paid at a competitive rate while others may be reimbursed through a pre-vocational payment methodology.

The graph below highlights the distribution of day service programs among all individuals who receive day services from OPWDD. This graph does not add up to 100 percent as people may participate in multiple programs. Most are enrolled in day habilitation (78.2%) with prevoc, supported employment (SEMP), and sheltered work closely trailing. At this time OPWDD is working on multiple initiatives to make employment the first option for individuals with developmental disabilities.

### Distribution of Day Service Programs for All Individuals Receiving Day Services (2011)



### **Campus-Based Treatment: Developmental Services (ICF/DC)**

Currently, New York State operates eight campus-based, Developmental Center (DC) settings. DCs provide ICF supports as described above in the community ICF model, but are operated on the grounds of Developmental Centers – they have a designation in Mental Hygiene Law as “State Schools” and can serve people who are remanded on an involuntary status through the courts or through a clinical determination of dangerousness. All of the campus settings provide supports to individuals who have specialized needs in one or more of the following areas:

- Intensive treatment for forensic risk management
- Mental Health support for people with dual diagnoses or severe emotional challenges
- Transitional treatment for individuals with Autism and severe behavioral challenges

There are individuals who are residing at campus-based settings who do not fit the above referenced profiles and who are in the process of transitioning into community supports. Additionally, efforts have been underway to restructure campus based settings to transitional settings where placement planning activities relate to established clinical criteria. There have been challenges to this initiative in part due to the lack of sufficient community supports to meet the clinical needs of individuals with these complex presentations.

### **Other Supports and Services**

There are also unique program options that have been developed by provider agencies or blended services that allow more customized person centered opportunities. Individuals’ needs often change over time and they require a different level of support at different points in their life. Annual reviews and related planning by responsible coordinators allow for appropriate assessment of the persons status and related changes needed to meet their changing life interests or treatment needs.

#### *Challenges Faced in Current System:*

- Gaining access to the appropriate supports when a person’s needs cross system boundaries can be a challenge (e.g., mental health and developmental disability);
- Crisis supports are not a discrete service category. There is variation across the state regarding how crises are managed; very often it is the individual in a crisis life circumstance that utilize high cost options which may not be clinically appropriate or cost effective.
- Accessing more individualized supports, like Consolidated Supports and Services, can be administratively complex and the availability varies geographically.
- Specialized behavioral supports are not readily available outside certified settings. Regulations place limits on the types of interventions that staff can employ when services are delivered outside a certified setting and without direct clinician oversight.

- New York lags behind other states in supporting employment for people with developmental disabilities.

## II. The OPWDD Current Fiscal Structure

The OPWDD funding is distributed across three budget categories: State Operations; Local Assistance and Capital.

### State Operations

State operations funding supports the personal and non-personal services required to operate all institutional and community programs, central coordination and support, and the Institute for Basic Research (IBR). During fiscal year 2011-2012, more than 22,000 State staff (Full Time Equivalent (FTE) basis) are required to support these programs.

- Institutional programs, which include Developmental Centers (DCs), Multiply Disabled Units (MDUs), Autism Units, Special Behavior Units, and Local and Regional Intensive Treatment Units (LITs and RITs), and Centers for Intensive Treatment (CITs). No DDSO has all of these programs, but several DDSOs have more than one type of institutional unit. Fewer than 1,300 people now reside in institutional units. OPWDD has as a goal closure of all DCs and the continued transition of people living in institutional units to community life as they become ready to make this move.
- All 13 DDSOs provide both State and not-for-profit operated residential, day and other non-residential services. State operations funding supports the more than 9,700 people who live in State operated homes and family care as well as day and other non-residential services. Most of OPWDD's State operations funding and FTEs support community services.
- Central coordination and support provides quality management, policy analysis, and administrative services such as budgeting, fiscal, human resources, and information services management.
- The Institute for Basic Research (IBR) is the research arm of OPWDD, located on Staten Island. In addition to groundbreaking research, IBR provides specialized clinical services through its Jervis Clinic.

### Local Assistance

Local Assistance funding provides for community services delivered to individuals with developmental disabilities by over 600 not-for-profit providers. Services include residential services, such as community homes (approximately 27,000 individuals), day and clinical services, and family support services.

- Most Local Assistance services are Medicaid services, delivered through either the HCBS Waiver or the State Plan. These services are paid for through the Department of

Health's (DOH's) eMedNY system according to rates set by OPWDD in collaboration with its provider community. Not-for-profit providers bill DOH for services and are paid through eMedNY. To reimburse DOH for the payments it makes to OPWDD providers, OPWDD periodically transfers funds to DOH to fund the State share of Medicaid. The total annual value of these transfers exceeds \$1.4 billion.

- Approximately \$380 million is used to support non-Medicaid services. In addition to paying for services provided to a small number of individuals who are eligible for OPWDD services but do not qualify for Medicaid, this funding provides for State Aid to counties to operate such programs as sheltered workshops. The other major program area funded is Family Support Services (FSS). The FSS program provides more than 72,000 services to more than 40,000 individuals with developmental disabilities and their families. FSS services include respite, which allows caregivers a break from caring for a loved one, recreation, information and referral.
- The remainder of the Local Assistance funding supports several large accounts that generate revenue.

### **Capital**

Nearly \$152 million in capital funding supports maintaining the State's capital infrastructure and assuring the health and safety of individuals with developmental disabilities in a quality physical environment. The funding is used for maintenance of existing facilities, the development of new and relocation of existing, State operated community residential and day opportunities, and for environmental modifications for people living at home.

# Care Coordination

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## Introduction

The need to provide coordinated care across providers, which aligns with the needs of the individual receiving services, has been a cornerstone of service delivery in the OPWDD system. Person-centered care coordination (i.e., service coordination) has been a key cornerstone of OPWDD's service delivery system. Currently individuals with developmental disabilities receive care coordination through several vehicles described below depending upon their individualized needs, residential living situation, and enrollment status in an OPWDD operated HCBS waiver:

- Individuals with developmental disabilities living in ICFs and nursing homes have care coordinated as part of residential service delivery.
  - ICF regulations require that all plans of care be implemented consistently and relate back to the comprehensive functional assessment (CFA) of needs.
  - Through the treatment team model and the role of the Active Treatment Coordinator (ATC) plans are developed with coordination and consistency as an expectation within the ICF setting.
- Individuals in the OPWDD Comprehensive Home and Community Cased Services (HCBS) Waiver must choose either targeted case management known as Medicaid Service Coordination (MSC) or an HCBS waiver service, known as Plan of Care Support Services (PCSS). Both MSC and PCSS are delivered by either OPWDD or not-for-profit providers known as MSC Vendors.
  - **MSC** is a Medicaid State Plan service which assists eligible persons (individuals with developmental disabilities needing “ongoing and comprehensive” service coordination) in gaining access to necessary supports and services appropriate to the needs of the individual. MSC is provided by qualified service coordinators (i.e., a service coordinator has at least an Associate’s degree in a human services field and one year of experience) and uses a person centered planning approach in developing, implementing and maintaining an Individualized Service Plan (ISP) (i.e., plan of care) with and for a person with developmental disabilities. The core services of MSC include: assessment, service plan development, implementation and maintenance, monitoring and follow-up, and related advocacy services. MSC is provided to approximately 81,000 individuals.

In October, 2010 OPWDD accelerated the redesign of the ten-year old MSC Program in response to the need for state financial plan budgetary savings of approximately \$30 million. In the MSC redesign, OPWDD emphasized mandate relief, increased administrative flexibility and paperwork streamlining and enabled flexibility in the provision of service coordination based on the needs of the individual—i.e., the mandated monthly face-to-face MSC Visit was reduced to a minimum of three times annually with additional face-to-face visits based on the needs of the individual and the professional judgment of the service coordinator. Mandated quarterly home visits were reduced to once annually with additional home visits based on needs and professional judgment of the service coordinator. Although program flexibility was increased and paperwork streamlined, the MSC fee-for-service decreased, the maximum caseload size was increased from 30 units to 40 units per service coordinator, and many MSC Vendors have had to make reductions in the service coordination workforce. The MSC redesign has resulted in divergent stakeholder opinions and feedback—while some individuals and families have welcomed these changes, others have come forward with strong opposition particularly to the reduction in the mandated monthly MSC face-to-face visit. These divergent feelings about the changes perhaps best illustrate the diversity of the people served by OPWDD and the great variety of need intensity to which any OPWDD program model must respond to.

- **Plan of Care Support Services (PCSS)** is a semi-annual service offered through the HCBS waiver and provided by qualified MSC service coordinators. Individuals who choose PCSS do not typically need ongoing and comprehensive service coordination. As a result, PCSS only typically provides assistance in maintaining and updating the required ISP and maintaining HCBS waiver eligibility by ensuring the completion of the annually required ICF/MR level of care redetermination. The number of individuals in the HCBS waiver accessing PCSS is small—only about 1,300 individuals vs. 81,000 accessing MSC.
- Children enrolled in the OPWDD Care at Home (CAH) Waivers (III, IV or VI) receive care coordination through one of the services offered through the CAH waiver known as **CAH case management**. Children with developmental disabilities enrolled in these waivers live at home with their families and are medically frail requiring intensive medical supports. The primary role of the CAH case manager is to ensure coordination of these medical services.

### *Challenges in Care Coordination*

- The different care coordination program models outlined above have promoted person-centered planning principles in the development of care plans for the individuals served, but may be more focused on care in the residential setting or on OPWDD community-based supports without addressing and integrating both health care and long-term care needs comprehensively.
- The current planning process does not always serve adults with developmental disabilities who have complex medical needs or individuals of any age who need psychiatric care in addition to developmental disability services. The person's care may be fragmented between health, mental health and developmental disability services and there is a structural lack of information sharing between providers making it difficult for a service coordinator to navigate complex administrative structures and to obtain timely information from providers in other systems.
- In addition, when an individual lives in a certified site the residential provider works in conjunction with the MSC to ensure that the needs of the person are met in a coordinated fashion. In uncertified settings the coordination of care can be more complex. Often the family or other natural supports play a critical role in coordination. Many individuals seek supports and services or act as advocates on their own behalf without the involvement or knowledge of the services coordinator. In these circumstances, coordinating the care in a manner that is consistent with best practices and best clinical outcome can become more difficult for the MSC.

In summary, major challenges include:

- Availability and accessing adequate resources to meet the person's needs;
- The experience level of service coordinators, and/or lack of experience and knowledge of complex systems, greatly impacts the effectiveness of service coordinators to assist people to meet their needs and goals.
- Ensuring services and treatment is coordinated when all information may not be available to the coordinator;
- Ensuring adequate communication between service and treatment providers, particularly with providers who are not part of the OPWDD system;
- Managing crisis needs; there is often a lack of available resources for an adequate and timely response to a crisis event; and
- The current fee-for-service system challenges care coordination and can make it difficult for service coordinators to receive timely information regarding service delivery.

# Financial Sustainability

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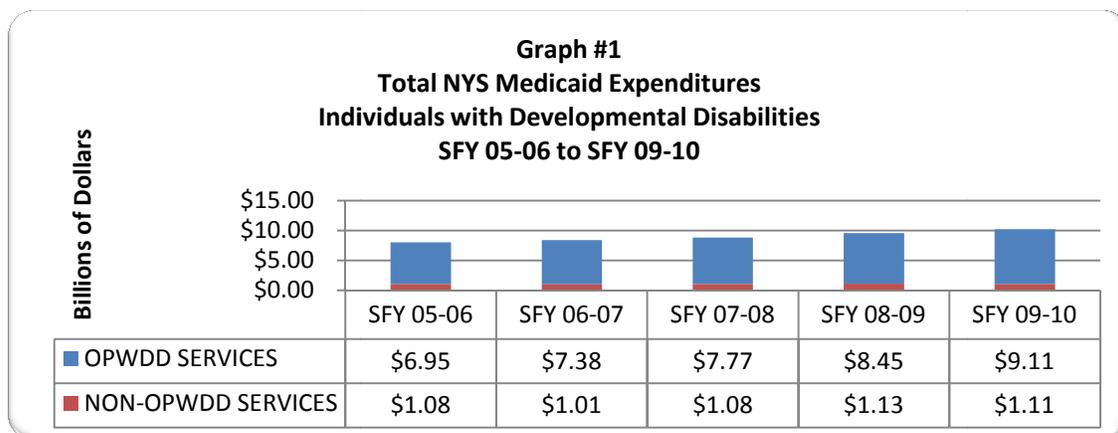
## Introduction

Medicaid is the primary funding mechanism for services to New York State's citizens with developmental disabilities. Approximately 90% of all services certified or overseen by the Office for People with Developmental Disabilities (OPWDD), as measured by public expenditure, are reimbursed through Medicaid program. Medicaid also plays a key role in funding long term care supports outside of the OPWDD service system --including nursing home, private duty nursing, personal care, and home health care services. Medicaid also funds special clinical supports to developmentally disabled (or delayed) children through the Early Intervention and School Supportive Health Services programs. Such services are often essential to attainment of full potential in intellectual development and functional independence. Medicaid funds the mental health and substance abuse services required by dually-diagnosed individuals. Finally, Medicaid plays a vital role, along with Medicare, in funding traditional medical services such as inpatient hospital, outpatient (services in hospital outpatient departments, free-standing clinics, and private practitioner offices), pharmacy, and ancillary healthcare services (laboratory, durable medical equipment, transportation, etc.).

This brief describes New York State Medicaid expenditures for individuals with developmental disabilities between state fiscal years 2005-06 and 2009-10. It is divided into five sections. Section one describes the global trends in term of total expenditures and individuals served by Medicaid and their implications regarding the long-term sustainability of the current system. Section two describes the current mechanism for funding OPWDD institutional (i.e., developmental center) services and why this mechanism will be changing under the People First waiver. Section three reviews expenditures for non-institutional OPWDD services and section four describes trends in non-OPWDD Medicaid services. Section five offers a summation of key points.

## I. Global Trends

Graph #1 below shows total Medicaid expenditures for individuals with developmental disabilities by state fiscal year for the five year period between April 2005 and March 2010. During this period, annual Medicaid expenditures increased by \$2.18 billion, with expenditures on OPWDD Medicaid services accounting for \$2.16 billion (99%) of this increase.



Below, Table #1 provides information on the five-year change in three key utilization measures: total payments, covered lives (i.e., member years, roughly equivalent to individuals served) and annual payments per covered life (PMPY). Nominal change, percent change over the five year period, and annual compound rates of growth are presented for each measure. Table #2 gives the comparative rates of growth observed in four key socio-economic indicators during the same time period.

**Table #1**  
**OVERALL MEDICAID UTILIZATION TRENDS**  
**FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**  
**(SFY 05-06 v. SFY 09-10)**

METRIC	SFY 05-06	SFY 09-10	CHANGE	% CHANGE OVER 5 YEARS	ANN GROWTH RATE
EXPENDITURE (State, local & Federal)	\$8,033,131,667	\$10,217,391,898	\$2,184,260,231	27%	6.2%
MEMBER YEARS	89,987	100,512	10,525	12%	2.8%
PER MEMBER PER YEAR (PMPY)	\$89,270	\$101,653	\$12,384	14%	3.3%

**Table #2**  
**COMPARATIVE GROWTH RATES: KEY SOCIO-ECONOMIC INDICATORS**  
**SFY 05-06 to SFY 09-10**

Measure	Annual Compound Growth Rate
Consumer Price Index (Northeast Urban) – All Items	3.26%
Consumer Price Index (Northeast Urban) – Medical Services Only	3.98%
Personal Income (New York State)	2.07%
Population (New York State)	0.27%

Several observations are immediately apparent:

- **Total Medicaid expenditure growth for individuals with developmental disabilities has outpaced the general inflation rate by nearly two times and personal income growth by nearly three times.** It has also significantly outpaced medical services inflation. It is highly unlikely that this rate of growth is sustainable over the long term.
- **Growth in payments per year of covered life generally followed the rate of overall inflation during the same period.** The high rate of nominal expenditure growth cannot be simply attributed to super-inflationary rate increases for service provision. Rate increases have generally followed overall inflation.
- **Thus, a primary driver of high expenditure growth has been the 2.8% annual growth in covered lives.** This has occurred while New York State's population has remained flat. The causes of this phenomenon are not fully understood and deserve additional study. However, three underlying demographic changes in the service system are thought to be contributing to this trend:
  - Improved life expectancy for individuals with developmental disabilities.
  - Expansion in OPWDD Medicaid services to children.
  - Growth in the Autism Spectrum diagnosis.

Factors other than demographic trends may also be at work. Initiatives to reduce waiting lists and expand service options (e.g., NYS CARES, Autism Platform) can draw new individuals into a service system. However, many of these same programmatic efforts have the underlying demographic trends discussed above as their main impetus.

## II. OPWDD Institutional Medicaid Services

OPWDD licenses three institutional service models funded by Medicaid: state-operated developmental centers and special residential units, and a voluntary-operated specialty hospital. Both provide all-inclusive non-acute services. This includes residential and day programming; nursing care; occupational, physical, and speech therapy; psychotherapy/behavioral health services; primary medical healthcare; pharmacy; and most ancillary healthcare services (including durable medical equipment, some laboratory services, and non-emergency transportation). Inpatient, emergency care, outpatient surgery, referred ambulatory, emergency transportation, and specialty medical services are not included in the institutional care package and are billed separately to Medicaid/Medicare.

Medicaid expenditures for institutional services have continued to grow significantly even as the institutional census has declined. See Table #3 below.

**Table #3  
MEDICAID UTILIZATION TRENDS  
OPWDD INSTITUTIONAL SETTINGS**

**SFY 05-06 to SFY 09-10**

<b>DEVELOPMENTAL CENTERS AND SPECIAL RESIDENTIAL UNITS</b>						
<b>METRIC</b>	<b>SFY 05-06</b>	<b>SFY 06-07</b>	<b>SFY 07-08</b>	<b>SFY 08-09</b>	<b>SFY 09-10</b>	<b>5 YEAR % CHANGE</b>
RECIPIENTS	1,757	1,740	1,733	1,660	1,586	-10%
BED DAYS	584,176	572,764	570,555	553,574	525,298	-10%
PAYMENTS (\$Millions)	\$1,912.1	\$2,121.3	\$2,132.9	\$2,271.6	\$2,399.7	25%

<b>SPECIALTY HOSPITAL</b>						
<b>METRIC</b>	<b>SFY 05-06</b>	<b>SFY 06-07</b>	<b>SFY 07-08</b>	<b>SFY 08-09</b>	<b>SFY 09-10</b>	<b>5 YEAR % CHANGE</b>
RECIPIENTS	53	54	53	54	52	-2%
BED DAYS	17,358	17,401	18,137	17,570	16,874	-3%
PAYMENTS (\$Millions)	\$15.9	\$15.9	\$16.6	\$16.1	\$15.5	-3%

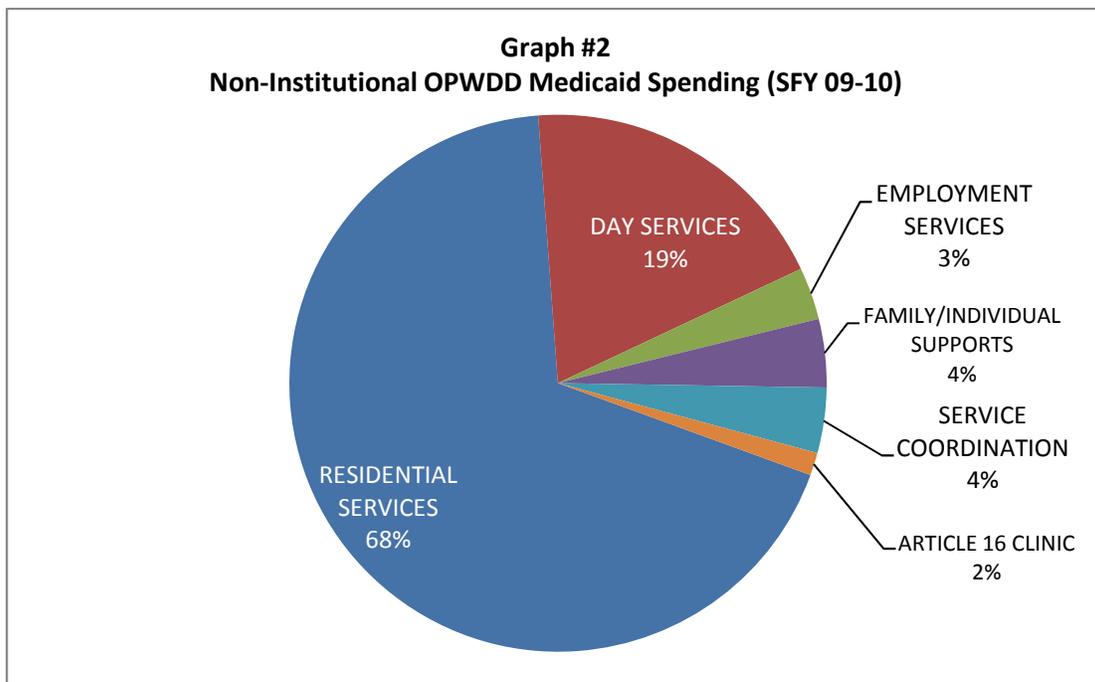
Various factors contribute to the growth in expenditures for developmental centers and special residential units. Key among them is OPWDD’s federally approved rate setting methodology for state operated institutions, which dates to the late 1980’s and was designed to incentivize community placements. This rate setting methodology, as prescribed in the Medicaid State Plan, takes into account certain costs associated with individuals that leave the institution (recognizing that many institutional costs, particularly capital costs, are fixed and remain even after census declines) and also allows for annual inflation adjustments. While effective in assisting the State to reduce the institutional census from over 9,000 individuals in 1988 to the present figure of approximately 1,300, the disconnect between actual institutional costs (as identified in state financial documents) from costs used in the rate methodology has, over the course of nearly 25 years, resulted in per diem rates that are difficult to explain to the general public. As a result, the creation of a new institutional funding platform will be a key element of the new 1115 Waiver agreement.

### **III. OPWDD Non-institutional Medicaid Services**

#### **Distribution of Spending**

Chart #2 below shows the distribution of expenditures for non-institutional OPWDD Medicaid services in SFY 2009-10. Nearly 70% of these expenditures were associated with residential services. The residential services category includes smaller, community-based

Intermediate Care Facilities (ICF's), Community Residences (CR's), Individualized Residential Alternatives (IRA's), and Family Care homes. Day services (day habilitation and day treatment) accounted for another 19% of expenditures and employment services (prevocational services and supported employment) added 3%. The remainder was made up of family and individual supports (respite, community habilitation, consolidated supports and services, family education and training) 4%, services coordination (Medicaid service coordination, Care At Home case management, and plan of care support services) 4%, and Article 16 clinic 2%. Given its oversized proportion of expenditures, residential services will likely play a central role in efforts to contain growth in future year expenditures.



### Utilization Trends

Table #5 below shows the nominal change, five year percentage change, and annual compound growth rates for expenditures and recipients within the six categories of non-institutional OPWDD Medicaid services. Again, we see that residential and day services accounted for most of the nominal expenditure growth during the five year period reviewed. The table also highlights the very high cost of residential services compared to all other service categories. It is nearly ten times more costly to place an individual into residential care than to provide individual and/or family supports that help maintain the person in his or her home. Likewise, traditional day services are significantly more costly when compared to employment related services. The recent high rates of expenditure and participation growth for family/individual supports and employment services reflect the efforts of OPWDD to

accommodate the increasing demand for these cost-effective alternatives to traditional residential and day programs.

**Table #5**  
**MEDICAID UTILIZATION TRENDS**  
**NON-INSTITUTIONAL OPWDD SERVICES**  
**SFY 05-06 TO SFY 09-10**

SERVICE	METRIC	SFY 05-06	SFY 09-10	CHANGE	5 YEAR % CHANGE	ANN GROWTH RATE
RESIDENTIAL SERVICES	PAYMENTS (\$ MIL)	\$3,529	\$4,571	\$1,042	30%	6.68%
	RECIPIENTS	33,334	37,805	4,471	13%	3.20%
	PAYMENT/RECIP	\$105,863	\$120,909	\$15,046	14%	3.38%
DAY SERVICES	PAYMENTS (\$ MIL)	\$939	\$1,283	\$344	37%	8.13%
	RECIPIENTS	36,853	38,956	2,103	6%	1.40%
	PAYMENT/RECIP	\$25,479	\$32,947	\$7,468	29%	6.64%
EMPLOYMENT SERVICES	PAYMENTS (\$ MIL)	\$133	\$212	\$79	59%	12.32%
	RECIPIENTS	15,433	17,491	2,058	13%	3.18%
	PAYMENT/RECIP	\$8,622	\$12,107	\$3,485	40%	8.86%
FAMILY/INDIV SUPPORTS	PAYMENTS (\$ MIL)	\$151	\$276	\$125	83%	16.28%
	RECIPIENTS	16,141	23,221	7,080	44%	9.52%
	PAYMENT/RECIP	\$9,340	\$11,869	\$2,529	27%	6.17%
SERVICE COORDINATION	PAYMENTS (\$ MIL)	\$200	\$263	\$63	32%	7.10%
	RECIPIENTS	70,052	82,414	12,362	18%	4.15%
	PAYMENT/RECIP	\$2,857	\$3,196	\$338	12%	2.84%
ARTICLE 16 CLINIC	PAYMENTS (\$ MIL)	\$70	\$91	\$21	30%	6.77%
	RECIPIENTS	31,960	28,975	(2,985)	-9%	-2.42%
	PAYMENT/RECIP	\$2,195	\$3,147	\$951	43%	9.42%

It is also important to look underneath the broad categories of expenditure described above. The cost of residential services, in particular, varies widely among program models. This is illustrated in table six below. When an individual, who could be placed in a supportive setting, must instead be placed in a more-restrictive and more-costly supervised setting –due to lack of local capacity, for example—the individual loses an opportunity for greater independence and the state will pay four times more, on average, for the higher level of residential care.

**Table #6**  
**Comparative Average Costs**  
**OPWDD Certified Residential Settings**  
**(SFY 09-10)**

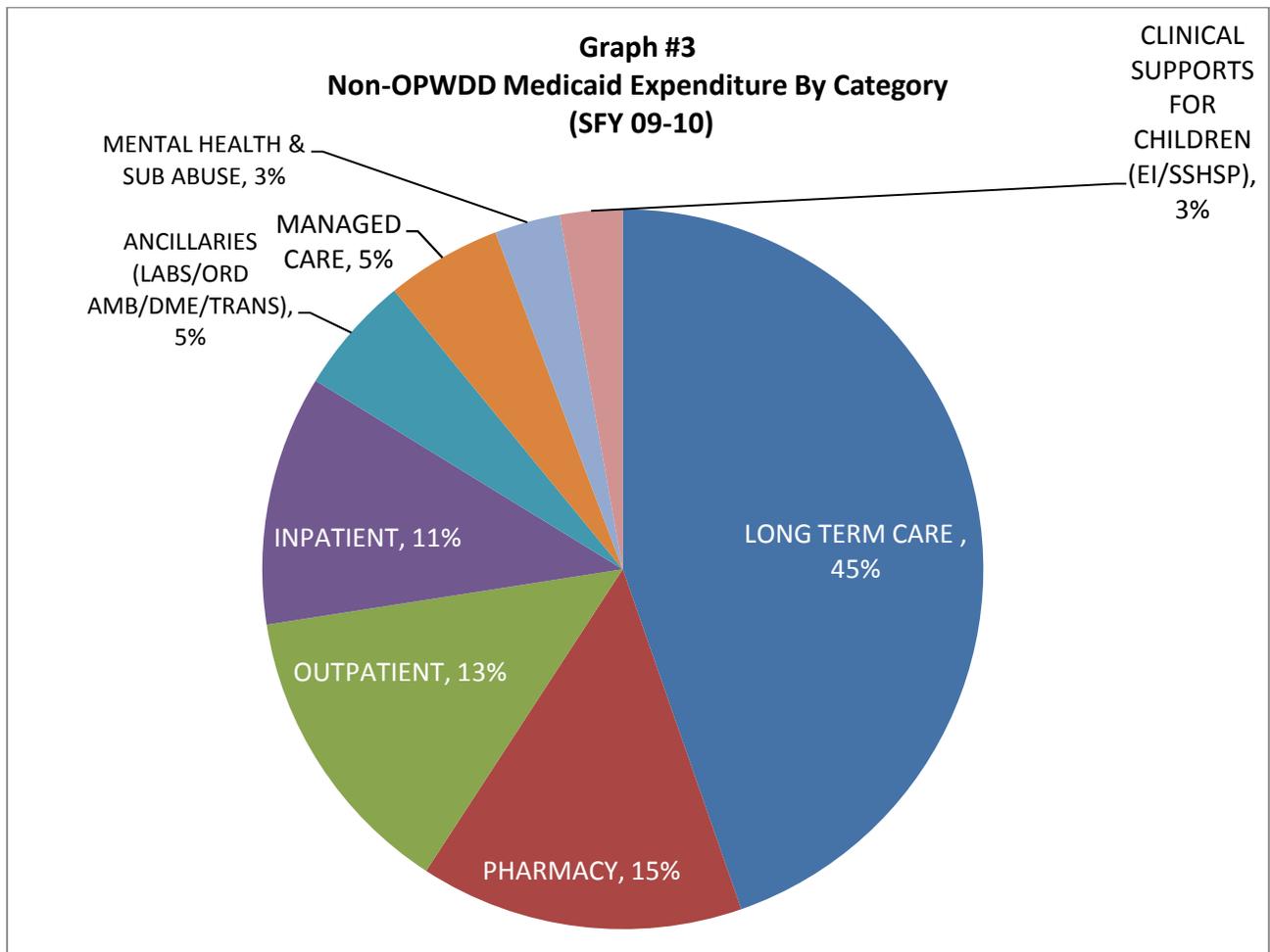
CERTIFIED RESIDENTIAL SETTING	FULL-YEAR PLACEMENTS	AVERAGE PAYMENT PER MONTH OF CARE
FAMILY CARE HOMES	2,534	\$1,383.59
SUPPORTIVE IRAs & CRs	2,020	\$4,068.16
SUPERVISED IRAs & CRs	25,641	\$11,205.90
INTERMEDIATE CARE FACILITIES (COMMUNITY)	6,130	\$13,724.99

## IV. Non-OPWDD Medicaid Services

### Distribution of Spending

The pie chart below shows the distribution of the \$1.1 billion in non-OPWDD Medicaid expenditures for the developmentally disabled population in SFY 2009-10. What may surprise many people is the extent to which individuals with developmental disabilities, in addition to accessing the long-term care supports and services overseen by OPWDD, also access the long-term care services overseen by the Department of Health (DOH). DOH long-term care services include: skilled nursing facility, personal care, certified home health agency, private duty nursing, and community services funded through DOH Medicaid waivers. Indeed, at 45% of all non-OPWDD Medicaid services, DOH long-term care was by far the most important driver of overall Medicaid expenditures outside of OPWDD services. Clearly, any attempt to control the growth of Medicaid expenditures for individuals with developmental disabilities must focus on the totality of long-term care services –irrespective of certifying agency.

This is not to say that traditional healthcare services are unimportant. Taken together, traditional healthcare services (pharmacy, outpatient, inpatient, managed care, and ancillary healthcare services) accounted for 50% of all non-OPWDD Medicaid spending. The remaining expenditures were associated with mental health and substance abuse services and special clinical supports for children (early intervention and school supportive health services).



### Utilization Trends

Table #7 below shows the nominal change, five year percentage change, and annual compound growth rates for expenditures and recipients within the nine broad categories of non-OPWDD Medicaid services. Because of high-interest, the author has separated out nursing home services from other DOH long-term care services in this display.

Table #7  
 UTILIZATION TRENDS  
 NON-OPWDD MEDICAID SERVICES  
 SFY 05-06 TO SFY 09-10

SERVICE CATEGORY	METRIC	SFY 05-06	SFY 09-10	CHANGE	5 YEAR % CHANGE	ANN GROWTH RATE
DOH LTC - NURSING FAC	PAYMENTS (\$ MIL)	\$81.87	\$96.95	\$15.08	18%	4.3%
	RECIPIENTS	1,778	1,923	145	8%	2.0%
DOH LTC - ALL OTHER	PAYMENTS (\$ MIL)	\$270.22	\$396.91	\$126.69	47%	10.1%
	RECIPIENTS	10,621	12,641	2,020	19%	4.4%
PHARMACY	PAYMENTS (\$ MIL)	\$282.06	\$160.59	(\$121.48)	-43%	-13.1%
	RECIPIENTS	77,013	72,245	(4,768)	-6%	-1.6%
OUTPATIENT	PAYMENTS (\$ MIL)	\$139.75	\$147.69	\$7.95	6%	1.4%
	RECIPIENTS	77,044	86,251	9,207	12%	2.9%
INPATIENT	PAYMENTS (\$ MIL)	\$108.52	\$124.27	\$15.75	15%	3.4%
	RECIPIENTS	10,295	12,013	1,718	17%	3.9%
ANCILLARIES	PAYMENTS (\$ MIL)	\$51.77	\$58.71	\$6.94	13%	3.2%
	RECIPIENTS	52,385	56,198	3,813	7%	1.8%
MANAGED CARE	PAYMENTS (\$ MIL)	\$16.80	\$57.19	\$40.39	240%	35.8%
	RECIPIENTS	6,227	13,060	6,833	110%	20.3%
MENT HEALTH & SUB AB	PAYMENTS (\$ MIL)	\$35.90	\$32.57	(\$3.33)	-9%	-2.4%
	RECIPIENTS	13,509	15,036	1,527	11%	2.7%
CLIN SUPP FOR CHILD	PAYMENTS (\$ MIL)	\$96.23	\$30.99	(\$65.24)	-68%	-24.7%
	RECIPIENTS	16,987	11,559	(5,428)	-32%	-9.2%

Certain service categories were impacted by external factors during the five year period reviewed. The large reduction in pharmacy costs is attributable to Medicare Part D, which shifted costs from Medicaid to Medicare. Similarly, the “clinical supports for children” category was affected by a federal investigation and subsequent settlement agreement. Interestingly, managed care participation nearly doubled during the five year period studied.

Because nearly all individuals with developmental disabilities are exempted from mandatory enrollment into managed care, the increase must have resulted from voluntary elections. This seems to suggest that the traditional misgivings toward managed care plans abated somewhat over the past five years.

Table #7 also reinforces, once again, the need to focus on long-term care services when seeking to limit expenditure growth. Non-institutional long-term care, in addition to being the largest non-OPWDD expenditure category, also ranked second in terms of annual expenditure growth during the five year period reviewed.

### Medicare: A Key Partner in Financing Traditional Healthcare Services

Medicare is a key partner in financing traditional healthcare services for seniors and adults with developmental disabilities. Nearly 60% of adults and over 95% of seniors are dually enrolled in Medicare. Because Medicare acts as the primary payer of most healthcare services for these individuals, it dramatically lowers Medicaid healthcare spending. This is illustrated in Table #8 below, which shows that Medicare reduces Medicaid’s healthcare expenditures for dually enrolled individuals by over 70%. This has important implications for cost containment strategies. For instance, any effort to improve care coordination/accountability, and, thereby, reduce emergency room visits and inpatient stays among the adult and senior populations would likely generate far more direct cost savings to Medicare than Medicaid.

**TABLE #8**  
**SFY 09-10 MEDICAID UTILIZATION**  
**INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES:**  
**IMPACT OF MEDICARE ENROLLMENT ON**  
**MEDICAID SPENDING FOR HEALTHCARE SERVICES**

AGE CATEGORY	MEDICAID ONLY ELIGIBLES	MEDICAID ONLY HEALTHCARE PMPM	MEDICARE DUAL ELIGIBLES	MEDICARE DUAL HEALTHCARE PMPM
CHILD (<21)	28,324	\$6,984.17	170	\$3,706.83
ADULT (21-64)	26,771	\$9,579.18	39,136	\$2,662.96
SENIOR (65+)	319	\$10,813.82	5,792	\$3,186.48

## V. Summation

The purpose of this brief has been to present basic information and review the significant trends in Medicaid utilization for individuals with developmental disabilities between the period SFY 2005-06 and SFY 2009-10. The author has also attempted to highlight facts and trends that may influence the development of an 1115 demonstration waiver. These include:

- Annual Medicaid expenditure growth for individuals with developmental disabilities exceeded 6.2% during the five year period reviewed. During the same period, general (all items) inflation grew by 3.3% per year, medical care inflation grew by 4.0% per year, and personal income grew by 2.1% per year. It appears unlikely that this rate of expenditure growth is sustainable in the long term.
- OPWDD services accounted for over 99% of the five year increase in Medicaid expenditures. Expenditures on non-OPWDD services were relatively flat during the same period.
- Expenditure growth has been driven by both inflation-based rate increases **and** increased demand for services. The increased demand for services requires additional study, but is thought to be linked with increased life expectancy, growth in individuals diagnosed with autism, and expansion of OPWDD Medicaid services for children.
- Although the institutional census declined by more than 10% during the five year period studied, Medicaid charges for institutional services increased by more than 25%.
- A key factor behind the growth in Medicaid charges for institutional services is a twenty year old rate methodology that decouples “actual” and “allowed” costs. This methodology played an essential role in the creation of the current community-based service system. Nevertheless, it has become progressively divorced from fiscal reality and requires replacement.
- Certified residential programs account for 68% of total Medicaid spending on non-institutional OPWDD services. Traditional day programs (i.e., day habilitation and day treatment) account for bulk (19%) of the remaining spending.
- One path toward reducing expenditure growth in OPWDD services is to develop and promote (perhaps through improved care coordination and individual resource allocation) desired and less-costly alternatives to traditional residential and day program models. In home supports are, on average, ten times less costly than placement in a supervised

residence. Employment related services are significantly less costly than traditional day programs.

- When traditional residential and day program placements are required, it is essential that the individual be supported in the least restrictive (and, typically, the least costly) setting. Serving an individual, who requires only supportive residential care, in a supervised setting increases costs, on average, by a factor of four.
- With respect to expenditures on non-OPWDD Medicaid services, DOH long-term care services predominate both in terms of total spending (45% of the whole) and spending growth (10% per year for non-institutional long-term care services). This growth in DOH long-term care services has been masked by external factors reducing expenditures in other non-OPWDD Medicaid service categories –most notably, pharmacy (Medicare Part D) and clinical supports for children (settlement agreement on school supportive health services).
- The significant use of DOH long-term care services by individuals with developmental disabilities may point to an opportunity for care coordination and cross-system accountability to improve personal outcomes while reducing total expenditures.
- Enrollment into managed care programs more than doubled during the five year period reviewed. This suggests that the traditional misgivings toward managed care held by many individuals with developmental disabilities may have abated somewhat.
- Medicare is a key player in financing traditional healthcare services for individuals with developmental disabilities. Approximately 45% of the OPWDD population is dually enrolled in Medicare. Such dual enrollment reduces Medicaid’s liability for healthcare services by over 70%. Efforts that reduce medical service utilization through improved care coordination and accountability may ultimately reduce Medicare expenditures far more than Medicaid expenditures. This should be considered when promoting the 1115 waiver to the federal government.

# Access and Choice

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## Eligibility

To understand the service system for people with developmental disabilities in New York State (NYS), it is helpful to know the definition of developmental disability and to have a sense of the prevalence of the covered conditions in the general population. Section 1.03(22) of the NYS Mental Hygiene Law defines developmental disability and is the basis for determining eligibility for 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 diagnosis of the disability.

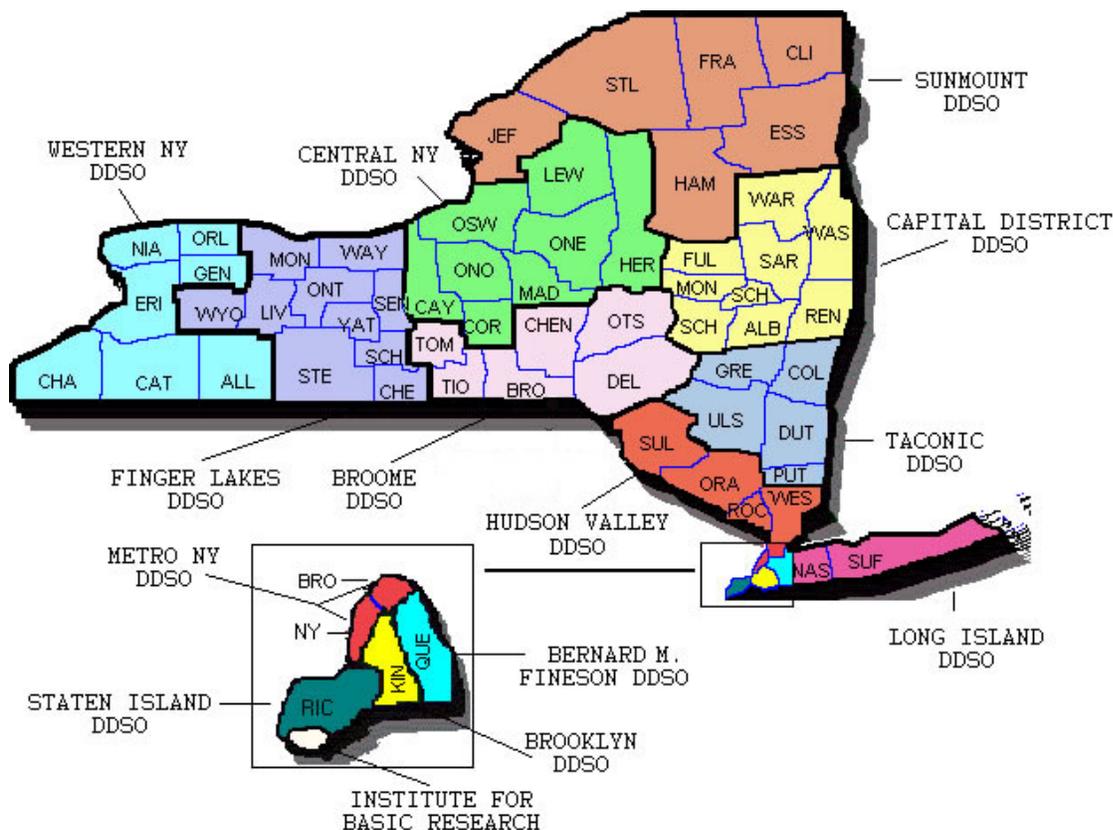
To increase the quality and consistency of eligibility assessments and awareness of the eligibility process and standards, OPWDD issued guidance documents that are posted on the OPWDD website making them available to individuals, families, providers and clinicians alike.

## Access

To access services from OPWDD a person must first be determined eligible. Eligibility is determined through review of the individual's diagnosis, age of onset and adaptive skills and deficits. Each OPWDD Developmental Disability Service Office (OPWDD) has a process to receive requests for receipt of services and a process for deciding and communicating eligibility. The expectations and factors to consider in determining eligibility are consistent across the state.

In addition to the requirements for OPWDD eligibility there are requirements for the Home and Community Based Services Waiver (HCBS waiver). The requirements include a developmental disability diagnosis (see above), eligibility for an ICF/MR Level of Care (need re-established annually), and eligibility/enrollment in Medicaid.

Currently, upon a determination of eligible, the individual is able to seek any available service option. Services are provided based on resource availability and an individual's priority need level. Individuals and their families will work directly with the appropriate OPWDD district office, known as OPWDD Developmental Disabilities Services Office (DDSO). The map below provides a visual display of the DDSO areas of responsibility.



Enhancing access to services is a cornerstone of OPWDD's vision, values, and mission. The important hallmarks that underpin greater access to services include:

- **Inclusion and equity.** DDSO processes are broadly inclusive. Multiple stakeholders such as families, individuals, self-advocates, local governments, and providers are invited to plan and identify needs, rank priorities, review proposals, and recommend funding. OPWDD will look to focus on potential and abilities, rather than disabilities. In addition, efforts to reach under-served communities and include new and emerging service providers are OPWDD priorities.
- **Balancing State and local priorities.** Local issues are recognized through local government planning, public forums, service registration, surveys, and other means to elicit and generate needs and ideas. These are coupled with articulated statewide OPWDD priorities that may include a variety of cross-State agency concerns such as children's services, health issues, and housing needs. Together, State and local priorities yield a finely balanced program to be implemented at the DDSO level.
- **Timeliness and transparency.** Access to services is effective only when processes are widely and commonly known and understood by the public, and decisions are timely and responsive. Maximum efforts to educate the public about available services, publish and distribute service applications, and involve stakeholders in decision-making are the cornerstone of DDSO systems. These processes are intended to be and must be seen as open, fair, and unbiased. Also, timeframes to review and decide on service requests must be rational and responsive, and understood by all participants, and provide opportunities for feedback.

Taken together, these efforts to enhance access to services build an OPWDD system that more closely links a broad array of supports with the families and individuals who need them the most. These hallmarks are all the more important as we work to distribute limited resources in this unprecedented fiscal environment.

#### *Challenges Faced in Current System:*

- Gaining access to the appropriate supports when a person's needs cross system boundaries (e.g., mental health and developmental disability);
- OPWDD has numerous providers all with varying areas of expertise; accessing the provider of best fit is a challenge;
- Accessing clinical evaluations needed to establish developmental disabilities is expensive and often made more difficult by lack of qualified practitioners in more rural areas;
- Needs assessment tools (the Developmental Disabilities Profile) is inconsistently applied; and
- Priority needs are not consistently managed across districts and agencies resulting in varying access to individuals.

## Choice

Choice is a principle that is imbedded within all facets of the OPWDD service system and viewed as the cornerstone of individualized services. Choice is important to each of us in our daily lives. The choices we make help to define who we are and the type of lives we lead. This includes everyday simple choices such as what to wear or eat, as well as life-defining choices such as where to live and work. For generations, persons with developmental disabilities have had their choices limited. Today, OPWDD is committed to improving people's quality of life by empowering them to make their own choices and follow their own dreams to the extent possible.

However, with choice often comes responsibility on the part of the individual, families and involved agencies. The importance of informed choice is highlighted, particularly when there is risk involved. Implicit in choice-making is the dignity of risk which recognizes that risk-taking is necessary for normal growth and development. However, the importance of balancing the right to choose with the right to be protected from unnecessary physical, psychological or social harm must be understood. Even with the best of intentions and commitment to facilitating making choices, barriers do exist. It is important to recognize such barriers and to find ways to overcome them in order to ensure a quality of life that includes choice, independence and responsibility.

### *Challenges Faced in Current System:*

- The breadth of available service options varies by geographic location;
- Resource availability for approved supports and services is frequently less than the service demand;
- The infrastructure to support more individualized service options is not well developed and differs geographically;
- Current administrative practice can limit portability and the individual's choice of services and providers; and
- Choice is restricted to the available options.
- The payment systems and funding are largely committed to institutional or less integrated/less flexible service systems.

# Quality

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The concept of quality is integral in the provision of services within the OPWDD system. Listening to the individual receiving services, families and advocates is at the core of the agency mission and comes from the premise that responsiveness to articulated interests and needs is paramount to providing quality supports. Inherent to quality practices is the concept of choice. Quality support options are meant to bring about the meaningful outcomes of personal health and safety, positive relationships, work and meaningful activities, and a desired home setting. To ensure quality, clear expectations are defined within all program models and oversight/certification practices are in place to evaluate the implementation of required actions and to review the effectiveness of the services in place. The regulations clearly define the expectation for reporting events in people's lives that require review, investigation, and remediation so that the likelihood of re-occurrence can be minimized. Regulations identify specific expectations related to the protections of individual rights and the general provision of services; these regulations clearly define the standards that guide quality. Quality activities within OPWDD are focused in the areas of appropriate service plan development, program/agency quality processes, OPWDD certification activities, and external oversight/monitoring activities.

## I. Program/Agency Quality Activities

The requirements for each program type vary and are defined in regulatory standards. All programs must set forth clear standards for services through the development of policies and procedures that are at least as stringent as the guiding regulations. Quality focused activities in the program/agency both lay the foundational practices and systems that support the adherence to the established standards and measure the effectiveness of those systems through internal quality management activities. A quality system of support includes:

- Advocacy and service coordination to meet individual needs
- Development of person centered care plans
- Appropriate implementation of care plans
- Ongoing training and education for staff
- Clinical/medical monitoring and response to emerging treatment needs
- Current and applicable policies and procedures
- An effective incident management system
- Internal controls to evaluate adherence to policies and procedures

The program/agency has a regulatory obligation to develop and implement these systems to ensure that quality standards are met.

## **II. Internal (OPWDD) Oversight**

### **Developmental Disabilities Service Office (DDSO)**

Each DDSO has a Quality Services department that oversees the quality aspects of the state operated service system. The department ensures that policies and procedures are implemented adequately and that DDSO programs are in compliance with guiding regulation. The department has direct responsibility for oversight of incident management practices of the state operated programs and for the certification of family cares homes operated within the district. The DDSO department also provides guidance to the voluntary agencies within the district related to incident management and regulatory compliance issues. The DDSO receives incident information from voluntary providers for the purpose of critical review and provides feedback to agencies regarding the appropriateness of the actions taken. When there is a need for direct observation and assessment in voluntary agencies a referral will be made to the OPWDD Department of Quality Management for compliance evaluation.

### **OPWDD Division of Quality Management (DQM)**

OPWDD's DQM is responsible for much of the quality management oversight activities in OPWDD, including monitoring all programs and services authorized or funded by OPWDD to ensure that safety and quality standards are met. The DQM is organized into several Bureaus and Units. Each Bureau/Unit plays a key role in ensuring that the services provided to individuals with developmental disabilities of New York State not only meet current standards of safety and quality, but that those services are continually improving in quality.

The quality practices of OPWDD's DQM are accomplished through the following organizational entities:

- Bureau of Compliance Management conducts limited fiscal review of a sample of voluntary providers annually in order to ensure they are fiscally viable and has appropriate systems for governance and administration.
- Incident Management Unit, newly created to oversee the implementation of sound incident management processes in state operated and voluntary providers.
- Quality Management Strategies Unit (QMS), a very small unit that continually evaluates DQM's activities and making recommendations for improvements. QMS works closely with OPWDD's Policy Unit to develop quality strategies for new programs and services. In the past year, QMS developed and implemented grouped authorizations of operating certificates; utilized IRMA data to target incident management reviews at provider agencies; worked with 12 advisory panels statewide of individuals, advocates, voluntary and state staff to obtain input to DQM as it revises survey and MSC protocols and implements a database to aggregate data needed to support compliance with OPWDD's HCBS waiver.
- Bureau of Program Certification (BPC), the DQM regulatory arm. The BPC conducts reviews using written protocols that contain standard requirements in such areas as

support of valued outcomes, waiver plan requirements, staffing and staff competencies, rights, health services, incident management, and physical plant and fire safety. The review protocols are based on OPWDD regulations applicable to all programs and services such as 14 NYCRR Part 624 (Reportable Incidents, Serious Reportable Incidents and Abuse); 14 NYCRR Part 633 (Protection of Individuals Receiving Services); and, 14 NYCRR Part 635 (General Quality Control and Administrative Requirements.) Part 635.10 also contains regulatory requirements for specific types of waiver services provided in New York State. In 2009, the review protocols were revised to include data collection for the assurances and sub-assurances listed in our HCBS Waiver. In addition, review protocols include regulatory requirements that pertain to specific certified programs. BPC uses three types of activities during its protocol reviews: Documentation review, Observation, and Interview.

## Summary of OPWDD DQM Certification and Surveillance Activities

### PURPOSE OF SURVEYS/REVIEWS:

Each DQM function is required by New York State Law, Federal Law and/or the Court-Ordered Willowbrook Permanent Injunction, as follows:

- **Certification and Surveillance of non-ICF certified programs:** *Article 16 of the Mental Hygiene Law* requires that all site-based programs certified by OPWDD be recertified at least every three (3) years. It also requires that every certified program receive two visits a year with an exception that a certified program may receive one visit a year if the program has a “*history of compliance and a record of providing a high quality of care.*” DQM currently reviews and certifies 6,900 non-ICF site-based programs.
- **Certification and Surveillance of Intermediate Care Facilities (ICF):** *Federal law, 42CFR Parts 442 and 483*, require that ICF programs receive a full recertification visit, including a full Life Safety Code review, at least one time every year with a validation of corrections during the year if deficiencies are identified. DQM currently surveys and certifies 555 ICFs.
- **Surveillance of Programs that serve Willowbrook Class Members:** *The Willowbrook Permanent Injunction* provides special requirements and monitoring for residential programs that serve class members. All Individual Residential Alternatives (IRAs) serving class members must receive a full certification review, including additional requirements specific to class members, every year. There are currently 749 certified IRAs that serve class members. In addition, annual partnership surveys must be conducted at a sample of family care homes that serve class members.
- **Review of Home and Community Based Services (HCBS) and Medicaid Service Coordination (MSC):** *The 1915 HCBS Waiver* that was approved by the federal government on October 1, 2009 and expires September 30, 2014, requires an annual review of a 10% sample of all waiver funded services and a 5% sample of all Medicaid service coordination authorized by OPWDD. DQM’s required sample review for 2009-2010 included approximately 9,500 Waiver reviews and 3,000 MSC reviews.

- **Monitoring of allegations of Child Abuse and Adult Abuse:** *14NYCRR Part 624* requires that DQM monitor that agencies implement incident management systems that comply with the law's requirements. DQM conducts at least an annual review of each agency's incident management practices. In addition, *the Child Abuse Prevention Act* requires that DQM monitors and reports to the Office for Children and Family Support (OCFS) regarding any allegation of child abuse they have confirmed or determined to be an allegation of institutional neglect and declined to investigate. The Adult Abuse Law requires that DQM work with OCFS to assess implementation of the law, produce an annual report to the governor and take joint remedial action if needed. During the last fiscal year, DQM conducted training for OPWDD staff and OCFS staff in several areas of New York State.

#### **METHOD OF REVIEW:**

Depending on the type of program or service being reviewed, the method varies. However, all surveillance and certification reviews are conducted via **site visits**. **All reviews include observation interviews and documentation review as described above.** The following is a general description of survey methods:

- **ICFs:** All ICF reviews are on-site visits. What is reviewed, how it is reviewed, and time frames for reviews are specifically prescribed by the federal government and cannot vary. The specific requirements for ICF reviews are found in 42CFR part 483, Appendix J.
- **Waiver-funded Services:** These are on-site visits. When Waiver services are provided at a certified site, the review is conducted in conjunction with the site review and includes observations of services being provided, interviews and review of records. When the Waiver services are provided in the community or a person's home, the review includes record review conducted at the provider agency's office and interviews of a sample of individuals who receive the services and their advocates if appropriate. Interviews may be conducted in person or by phone. In some cases, DQM reviewers utilize the *National Core Indicators (NCI)* interviews as the tool to focus interviews. As required by OPWDD's HCBS Waiver, the reviews of Waiver services include a review of the Quality Improvement assurances and sub-assurances specified in the Waiver guidelines written by the federal government. The data obtained from Waiver reviews is entered into a statewide database that provides the information needed for annual mandated reporting.
- **MSC Services:** These are on-site reviews. When the MSC record and the MSC are available during review of a certified site, the MSC review is conducted at the time of the certified site review. In other cases, the process includes a review conducted at the provider agency's office. All MSC reviews include interviews of a sample of MSCs, individuals who receive the services and their advocates if appropriate. Standards used in the review of MSC services include the quality values for MSC as identified by OPWDD and the Quality Improvement assurances and sub-assurances specified in the Waiver guidelines written by the federal government. This review also includes a vendor-level review of the agency's self-assessment activities. Interviews may be conducted in

person or by phone. In some cases, DQM reviewers utilize the *National Core Indicators interviews* as the tool to focus interviews. As required by OPWDD's HCBS Waiver, data obtained from MSC reviews is entered into a statewide database that provides the information needed for annual mandated reporting.

- **Surveillance of Programs that serve Willowbrook Class Members:** This is a mandated annual on-site review. Activities and standards in this review are the same as a full recertification survey with the addition of some specific court-ordered mandates.
- **Monitoring of Allegations of Child Abuse:** These visits are generally on-site validation visits to verify that the agency or program has implemented the plan of correction approved by OCFS and that the plan of correction is effective to prevent continued abuse.
- **Certification and Surveillance of non-ICF certified programs:** Certification and surveillance reviews are always conducted on-site. Depending on the type of review and the type of program being reviewed, this function includes several different activities and methods. Following is a brief description of some of the activities and methods being used:
  - **Initial certification of an agency or program.** This activity involves a desk review of the character and competence of the governing body, a review of the need for the program, and a review of an agency's policies and procedures to ensure that there is evidence that the agency/program can deliver safe and effective services in compliance with OPWDD regulatory requirements. When a program or service is ready to begin operation, OPWDD conducts an on-site visit to ensure that the program has an adequate site (if applicable), equipment and staffing to provide safe and effective services.
  - **Recertification and surveillance activities:** There are five different methods that are used to implement this function. All are on-site reviews.
    - **Central Review of agency-wide processes required by regulation:** There are many agency processes required by regulations for all program types. These can be reviewed one time yearly at the agency's main office, rather than at each site visit. Examples include: staff hiring, staff training, infection control practices, criminal background checks, etc.
    - **Full certification reviews:** OPWDD staff conducts on-site reviews of regulatory requirements that are specific to that site and program type. On-site reviews include observation, record review and interviews and focus on health and safety of individuals being served as well as the quality of the specific services being provided by the site. In some cases, DQM reviewers utilize the *NCI interviews* as the tool to focus interviews.
    - **Annual reviews of programs:** During fiscal years when a full recertification visit to a program is not required, OPWDD staff conducts an "annual visit" to a program site. This on-site visit targets select health and safety indicators such as fire safety and may include review of selected quality indicators in one or more of OPWDD's value areas such as participation as a member of the community.

- **Complaint Investigations:** OPWDD always responds to complaints received from individuals, advocates, and other stakeholders such as lawmakers, other state agencies, etc. Upon receipt, all complaints are screened to determine the immediacy of action that is required. In some cases, survey staff will be immediately dispatched to assess the situation due to the severity of the allegation. If immediate staff action is not required, complaint investigations may involve one of two methods. In a case in which a complaint has not been communicated to the provider agency and the agency has not been given a chance to respond, OPWDD will make the complaint known to the provider agency and require that the agency investigate and respond to the complaint in a specific time frame. OPWDD follows up that the agency has taken appropriate and effective action and that the complainant is satisfied with the action taken. In cases in which the provider agency has been informed of the complaint and has not taken appropriate action to address it, OPWDD conducts a site review to investigate the issues that form the basis of the complaint. If the complaint is substantiated, OPWDD requires that the provider agency develops and implements a plan of correction to address the deficient practice(s). Depending on the nature of the deficient practice(s) identified, a second visit may be conducted to validate correction.
- **COMPASS:** OPWDD developed the COMPASS concept to recognize agencies that consistently provide high quality programs, supports and services. COMPASS promotes and relies on an agency's self-assessment activities rather than detailed and comprehensive reviews conducted by OPWDD. The programs and services provided by COMPASS agencies do not receive annual on-site reviews by OPWDD. Rather, the COMPASS agency conducts the reviews and reports annually to OPWDD. OPWDD conducts one verification visit annually to a COMPASS agency. The one visit includes validation of self-assessment activities implemented by the agency in their programs and services.

### III. External Oversight

#### New York State Department of Health (DOH) Campus Based ICF/DCs

The NYS Department of Health (DOH) is responsible, through contract with the Federal CMS, to complete annual certification surveys in all ICF/DCs in NYS. The surveys are conducted using clearly defined protocols consistent with federal guidance to evaluate the program against the standards identified in the guiding federal regulations. Upon survey completion, a Statement of Deficiencies (SOD) is issued, where warranted, and Plans of Corrective Action (POCA) are developed by the program. Upon acceptance of the POCA an operating certificate is issued by DOH. DOH also completes a post certification review to ensure that the plan of corrective action has been implemented adequately and that any deficiencies were corrected. DOH in coordination with the federal Center for Medicaid Services (CMS) has the ability to initiate sanctions if a DC is not meeting required standards and does not correct the deficiencies identified in a timely manner.

## **Office of Fire Prevention and Control (OFPC)**

To ensure the most effective fire safety practices within the system of care for individuals served in certified settings, OPWDD partnered with the OFPC. As agreed upon in the April 2011 Memorandum of Understanding between OPWDD and OFPC, effective August 2011, OFPC staff will participate in the fire safety and physical plant survey activities for all 24 hour supervised residential facilities as well as pre-opening reviews for all new 24 hour supervised residences. OFPC will utilize the same codes and regulations as DQM/BPC survey staff including NFPA Life Safety Codes, Part 483 for ICF's and applicable State regulations such as Part 635. OFPC survey activity results will be conveyed using established OPWDD processes including Exit Conference forms and SODs. SODs, if warranted, will be issued by OPWDD and POCAs will be returned to OPWDD for review. In addition, OFPC will partner in the development of a fire safety training curriculum that will be utilized system wide.

## **Commission on Quality Care and Advocacy for Persons with Disabilities (CQC)**

CQC is responsible for the independent oversight of the programs certified and operated by OPWDD, The Offices of Mental Health (OMH) and Alcoholism and Substance Abuse Services (OASAS). CQC receives all reports of alleged abuse and of deaths in the mental hygiene system. They complete independent reviews where they determine such are needed. Additionally, primary investigations are completed for reports of child abuse in designated programs and recommendations are made to the Office for Children and Family Services' (OCFS), State Central Register (SCR) as to the disposition of the allegation. Upon the completion of reviews and investigations, findings are issued and recommendations are made to the appropriate entities to improve the system of care. CQC also serves as the Protection and Advocacy (P and A) agency under federal standards; contract offices are in place to implement the P and A function. Legal advocacy is the hallmark of the P and A offices. CQC also supports quality through training initiatives, publications of best practices, systemic evaluation of specific programs and new program models, and with information and referral activities.

## **Mental Hygiene Legal Services (MHLS)**

For individuals living in certified settings, MHLS provides legal advocacy and direct representation in circumstances where individual rights are in question.

## **Office of Medicaid Inspector General (OMIG)**

OMIG is responsible for ensuring that the billing and payment practices are consistent with the established standards for receipt of reimbursement. They ensure compliance with the defined documentation standards for services delivered. The focus of the compliance activities is to ensure that Medicaid funds are spent on appropriate services and that the documentation supports the delivery. If OMIG findings identify practices that are not consistent with the

established standards they have the authority to recoup Medicaid funds from provider agencies.

#### IV. Summary

Quality is embedded within the system of care in numerous ways. There are clear standards of care and rigorous monitoring and oversight practices related to ensuring that individuals served within the OPWDD system are receiving supports consistent with their needs. Individuals living in certified living settings have a great deal more oversight and the accountability regarding the delivery of supports is much higher than for those who are supported in non-certified settings. As the system shifts to provide supports to individuals and families in settings that are not certified the focus on quality needs to be more fully incorporated into measurable outcome metrics for individuals in the areas of personal health and safety, work and meaningful activities, desired home settings, and the development of positive relationships.

Through the People First Waiver, New York will develop an integrated, comprehensive quality framework driven by performance metrics that are linked to personal outcomes for individuals with developmental disabilities. This will include system-wide analysis and collaboration that lead to effective remediation strategies, quality of care enhancements, and ultimately, mission-driven progress. Milestones of the expanded quality framework will include: using metrics to measure both individual outcomes and system performance and drive policy and fiscal decisions; promoting and rewarding excellence by incentivizing high quality compliance plans and voluntary compliance; using risk analyses and technology to target state Quality Management resources in the most efficient and effective manner; developing appropriate enforcement levels when program and/or fiscal compliance is systematically or intentionally breached.

#### *Challenges Faced in Current System:*

- Applying quality expectations for treatment approaches in uncertified settings. Although DQM processes have evolved over the thirty-year history of the agency, the design of quality reviews are in many ways tied to service delivery in certified settings although current trends are toward service delivery in non-certified settings (e.g., the person's own home).
- Current processes are in a state of flux as DQM has been tasked to revise its certification and surveillance practices to better promote agency self-assessment and to include a measurement of quality of services as well as regulatory requirements.
- OPWDD implemented a new on-line incident reporting application (IRMA – Incident Review and Management Application) and is working with its not-for-profit agencies to ensure that incidents are uniformly reported statewide.
- Ensuring that quality is measured in a metrics driven process.