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Governor



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New York State Office For People With Developmental Disabilities

Statewide Comprehensive Plan

2011-2015



October 1, 2011

Executive Office

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Dear Friends and Colleagues:

I am pleased to share with you the New York State Office for People With Developmental Disabilities' (OPWDD) Statewide Comprehensive Plan for 2011-2015.

The plan outlines the strategic direction for OPWDD over the next five years. The new direction for OPWDD and its partners will be facilitated through the development and implementation of an 1115 Research and Demonstration Waiver called the People First Waiver. All Medicaid services and supports for individuals with developmental disabilities will ultimately be funded and managed through this new waiver agreement between New York State and the Centers for Medicare & Medicaid Services (CMS). The hallmarks of the new system that will be built over the next five to ten years will include:

- A “no wrong door” approach that enables people to access supports and services through multiple points of entry;
- Assessment tools that accurately determine the level of support and allocate resources equitably to individuals across the system based on their strengths and needs rather than historic program costs;
- Coordinated care organizations that assist individuals with the coordination of all of their Medicaid and other service needs;
- A quality framework based on personal outcomes and proven health and safety measures;
- An infrastructure that ensures fiscal sustainability while providing more flexible supports and service options to individuals in the least restrictive setting; and
- Expanded capacity to provide appropriate clinical, behavioral, and medical supports to more people in community settings.

For individuals with developmental disabilities and their families, this means that access to services will be easier and there will be greater opportunities for choice and control over supports. In the past, coordinating care meant putting individuals into existing programs where there was availability. Now, OPWDD will start with the person first, assess his or her ability level and preferences, and then develop a person-centered plan that will encompass all Medicaid-funded supports and services, and work to build an individual's capacity for greater independence and life fulfillment based on their strengths and interests. Through redesigning the system, we hope to serve New Yorkers holistically through provision of long-term supports traditionally funded by OPWDD along with physical health, mental health, and substance abuse and other supports across systems. The People First Waiver will help OPWDD accomplish its goal of deinstitutionalization by expanding the capacity of home and community based clinical and behavioral supports to enable individuals to transition to the community successfully and receive services in the least restrictive setting.

At this time, OPWDD, in partnership with a representative group of stakeholders, has completed its initial design work and is beginning to develop the waiver application that will be submitted to CMS. We anticipate approval to begin designing and implementing pilot projects in 2012 based upon the reforms in this report and the input we receive from you—our stakeholders.

Much has been accomplished in six short months due to the commitment and teamwork of multiple stakeholders. I would specifically like to thank the 1115 Waiver Design Teams and the Steering Committee for their collaboration on this initiative as well as the New York State Department of Health. The participation of individuals, self-advocates, family members, providers, and state staff have enriched the design process through a strong partnership that I know will continue as we begin the next phase of the People First Waiver development.

Sincerely,

A handwritten signature in black ink, appearing to read 'Courtney Burke', written in a cursive style.

Courtney Burke
Commissioner



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Overview

The Office for People With Developmental Disabilities (OPWDD) is pleased to present the Statewide Comprehensive Plan for 2011-2015. This plan describes OPWDD's strategic direction for the next five years as we transform the developmental disability service system to be more responsive to the needs of individuals with developmental disabilities and their families. Over the past 33 years, the organization experienced several significant paradigm shifts and is currently embarking on a new development phase to better support this population. The new direction for the agency will be the implementation of the People First Waiver.

The People First Waiver is the result of nearly five years of strategic planning, starting with OPWDD's participation in the Real Choice System Transformation Grant funded by the Centers for Medicare and Medicaid Services (CMS). The grant provided OPWDD with an opportunity to critically examine the existing service system in New York State, research exemplary practices and determine the best course of action for a system redesign, emphasizing choice, quality and equitable funding. As a result, the agency operationalized plans to retain a strong direct support workforce, infuse person-centered principles into service planning, develop individualized housing options, and expand self-directed services. The grant was instrumental in leading OPWDD toward change; however, to date, this change has been more incremental than systemic. The agency realized that it needed to redesign its infrastructure and modify agreements with other state and federal agencies to truly implement a "people first" model for service delivery.

As the grant period ended, the effects of health care reform and the recession started to impact NYS. It was clear that one of the largest Medicaid programs in the country could no longer be administered as it had been. The State needed to take action to redesign Medicaid so the program not only met the needs of New Yorkers, but did so in a way that was well coordinated and fiscally responsible. Recognizing this, newly elected Governor Cuomo established the Medicaid Redesign Team (MRT) to review the Medicaid program and provide recommendations for fiscal and programmatic reform. The recommendations from the MRT were the impetus for redesigning the OPWDD system to better actualize the mission and vision of the agency.

The People First Waiver is the vehicle for implementing systemic change by transitioning services in OPWDD's 1915(c) Home and Community Based Services (HCBS) Waiver and State Plan services to an 1115 Demonstration Waiver. This demonstration waiver will allow New York to continue to obtain federal funds to support services to individuals with developmental disabilities while it develops and demonstrates important programmatic, administrative, quality and fiscal reforms. Essentially, the new waiver will support OPWDD to advance the system's capacity to deliver more quality, choice and community engagement to those we support while modernizing fiscal, administrative, and quality operations to ensure sustainability for years to come. This demonstration waiver will also incorporate other Medicaid long term care and acute services that are provided to individuals with developmental disabilities.

The People First Waiver will demonstrate that:

- Better coordination for individuals with extremely complex medical/behavioral health needs can be achieved through specialized systems of care management or coordination.
- A long-term care delivery system that places person-centered planning, individual responsibility and self-determination at the forefront can enhance care, individual satisfaction and lower Medicaid costs.
- New reimbursement models for institutional and community-based care systems promote efficiency, improve accountability and reduce costs.



- The continued provision of essential mental hygiene services through the establishment of a safety net care pool will provide lower-cost services that meet individual needs and defer entry into higher cost Medicaid options.

OPWDD has steadily worked on the design of the 1115 waiver, first through a statewide discovery process that included listening sessions, forums and online surveys, and second, through the creation of a steering committee, stakeholder design teams and a unit specifically charged with managing the project. Much progress has been made in the past six to seven months, and much more will be accomplished over the course of the five year demonstration.

The Statewide Comprehensive Plan shares OPWDD's strategic direction for system transformation through the next five years as the organization transitions to the People First Waiver and a managed care system for delivering acute and long-term care.



Mission and Vision Statements: OPWDD's Commitment to New Yorkers

Mission

We help people with developmental disabilities live richer lives.

Vision

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.

Values

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 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.

The People First Waiver will change the way OPWDD has historically done business, however; the mission and vision that guide the agency and its many partners remains the same. The People First Waiver reforms will support OPWDD's service system to deliver improved outcomes for the individuals it supports and demonstrate its guiding principles in more visible and measurable ways. The new waiver will improve our ability to meet the diverse needs of individuals with developmental disabilities and to offer them greater choice and flexibility in creating an effective, individualized plan of support. The mission and vision statements are about improving quality of life; specifically, OPWDD is committed to achieving five outcomes for people with developmental disabilities:

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

These five outcomes provided consistent direction to the agency over the past five years and contributed to the development of key services and initiatives such as Community Habilitation, Intensive Behavioral Supports, Employment First, the Portal, and the Autism Platform. The People First steering committee and design teams would return to these outcomes periodically as they began mapping out what the future service delivery system would look like.

OPWDD also remains steadfast to its values and guiding principles. Values describe how OPWDD employees interact with individuals, families, staff, the community, and each other. Guiding principles frame how the agency conducts business.



OPWDD's Guiding Principles

Put the Person First – People with developmental disabilities are 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 business.

Maximize Opportunities – OPWDD's vision of productive and fulfilling lives for people with 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 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.



Background

Historical Context

In 1978 OPWDD separated from the Department of Mental Hygiene when the predominate service options available to individuals and families were in state operated institutions. At the time, 15,000-20,000 individuals lived in institutional settings and the agency was in the beginning stages of transitioning individuals to the community. New congregate, medically based residential models emerged such as intermediate care facilities (ICFs) and community residences (CRs). For day activities, people with disabilities started attending day treatment programs and sheltered workshops. These were the first types of day services that were not co-located with the residential setting. Although both residential and day programs were still segregated, they offered individuals greater opportunities to engage in community life.

By 1991, the HCBS waiver was approved by CMS and OPWDD developed the capacity to serve individuals in their own homes or family homes. Services such as at home residential habilitation, respite and family support services were designed to help people to continue to live with their families; and day habilitation, prevocational services and supported employment were created to provide individuals with meaningful activities during the day. The HCBS Waiver served individuals and families well since the 1990s and was instrumental in transitioning and diverting people from segregated institutional settings.

Eventually OPWDD adopted a person-centered approach to service planning with the goal of building its capacity for individualized and self-directed supports. By the 2000s, individuals had opportunities to purchase or rent their own homes, and hire and manage their own staff with support from providers. Overall, deinstitutionalization and the HCBS waiver allowed OPWDD to develop one of the largest developmental disability systems in the country, with more than 600 nonprofit providers, serving more than 126,000 people by 2011.

Having a large developmental disability system is beneficial to residents of New York State (NYS) because there is a plethora of Medicaid services and supports available to meet the needs of individuals and families. For example, few States have the ability to offer the number of certified residential opportunities that exist in NYS and even fewer states are able to serve over 100,000 people. But constant expansion of Medicaid funded programs is not beneficial when services are provided in various silos, lacking coordination of care. Individuals, families and professionals find the system difficult to navigate, and it is clear that NYS can no longer fiscally sustain the level of development that occurred in the 1990s and early 2000s.

New Realities

Health care in the United States is not like it was 30 years ago, not for ordinary citizens or people with developmental disabilities, and much more is going to change in the coming years with the implementation of Health Care Reform and the Affordable Care Act. OPWDD has been facing a number of trends that led the organization to the People First Waiver.

First, the life expectancy of people with developmental disabilities is almost at parity with the general population. People with moderate to severe intellectual disabilities can expect to live well into their late 60s and late 50s, respectively. These findings are evident in OPWDD's demographic data. Figure 1 shows that the number of individuals over age 50 has grown to almost 25 percent of the population. Similarly, the agency is experiencing an influx of children entering the DD system with families requesting services to complement the special education their children receive from the public

education system. The percentage of children served by OPWDD has doubled since 1989. OPWDD, the State Education Department (SED), and the Office of Children and Family Services (OCFS) must work collaboratively to ensure in-state services are available for this special population.

Figure 1. Individuals Age 50+ and Age 21 or Less: 1989-2011

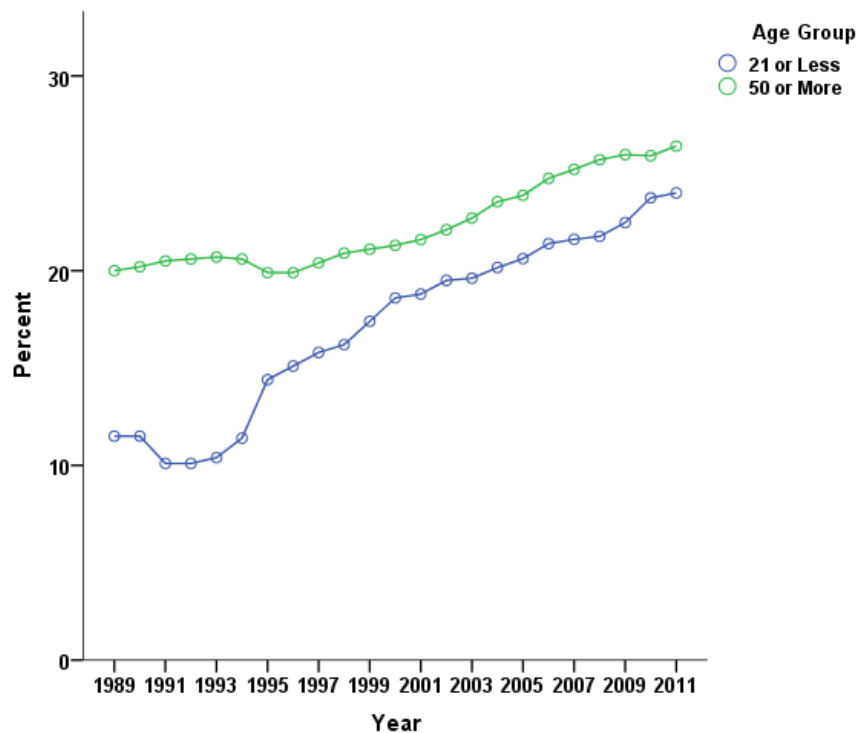
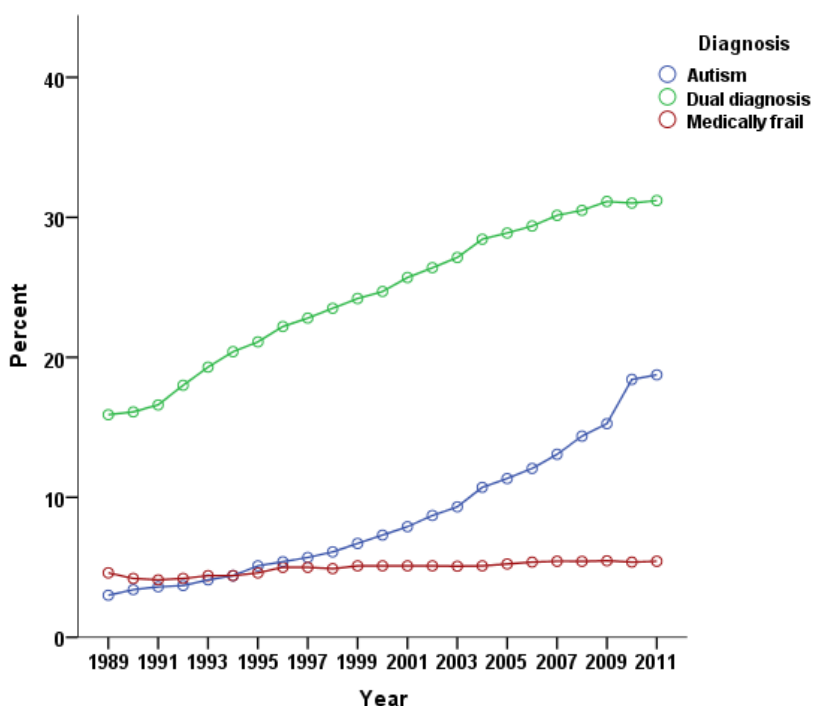


Figure 2. Trends for Autism, Dual Diagnosis and Medical Frailty: 1989-2011



Second, it is less common for individuals to have a sole diagnosis of intellectual disability. Rather, people often present with multiple physical or cognitive conditions that require specialized or intensive treatment. Figure 2 demonstrates the increase in the percentage of individuals with dual diagnosis, autism spectrum disorder and medical frailty. Individuals who are medically frail have multiple medical conditions which result in high self-care needs, profound motor challenges and more intensive staff support. This population reached the level of 5.5 percent of all individuals served in 2011. Dual diagnosis of a developmental disability and mental illness has grown to over 30 percent,

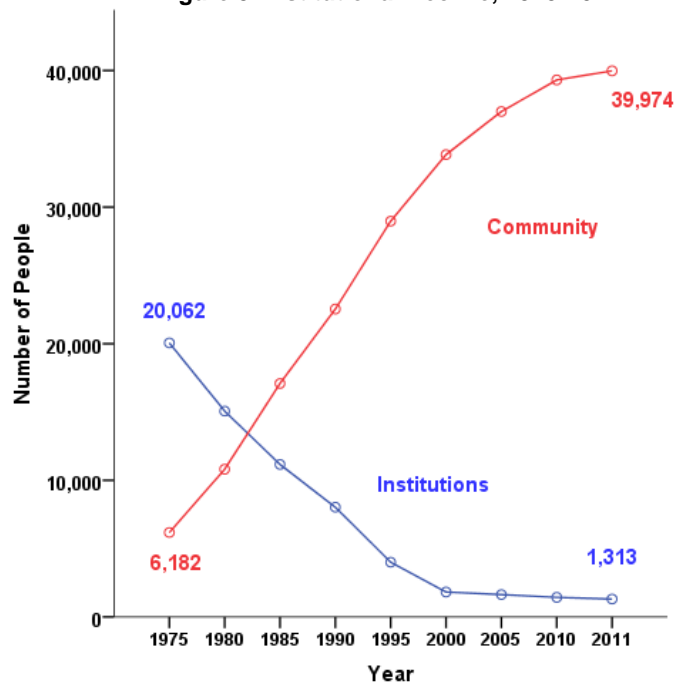
doubling within the past 22 years. Even more striking is the rapid growth of Autism Spectrum Disorder (ASD). During the same period (1989-2011) and consistent with national trends, the percentage of people with autism increased by 500 percent.

The complexity of the physical and behavioral health needs of individuals with developmental disabilities not only requires OPWDD's menu of habilitation and clinical services, but also the expertise of other systems such as mental health, substance abuse and various acute and chronic care providers. For many years, the agency successfully addressed developmental disabilities, but without fully developing the capacity to coordinate the care of individuals with cross-system needs. For the future, it is imperative for the OPWDD system to partner with individuals and families, and coordinate services in a holistic manner.

Overarching factors such as federal initiatives and economic conditions are also changing OPWDD's traditional operating environment. In 1999 the U.S. Supreme Court ruled in *Olmstead v. L.C.* that under the Americans With Disabilities Act (ADA) unjustifiable institutionalization of a person with a disability who, with proper support, can live in the community is discrimination. In its ruling, the Court said that institutionalization severely limits the person's ability to interact with family and friends, to work and to make a life for him or herself.

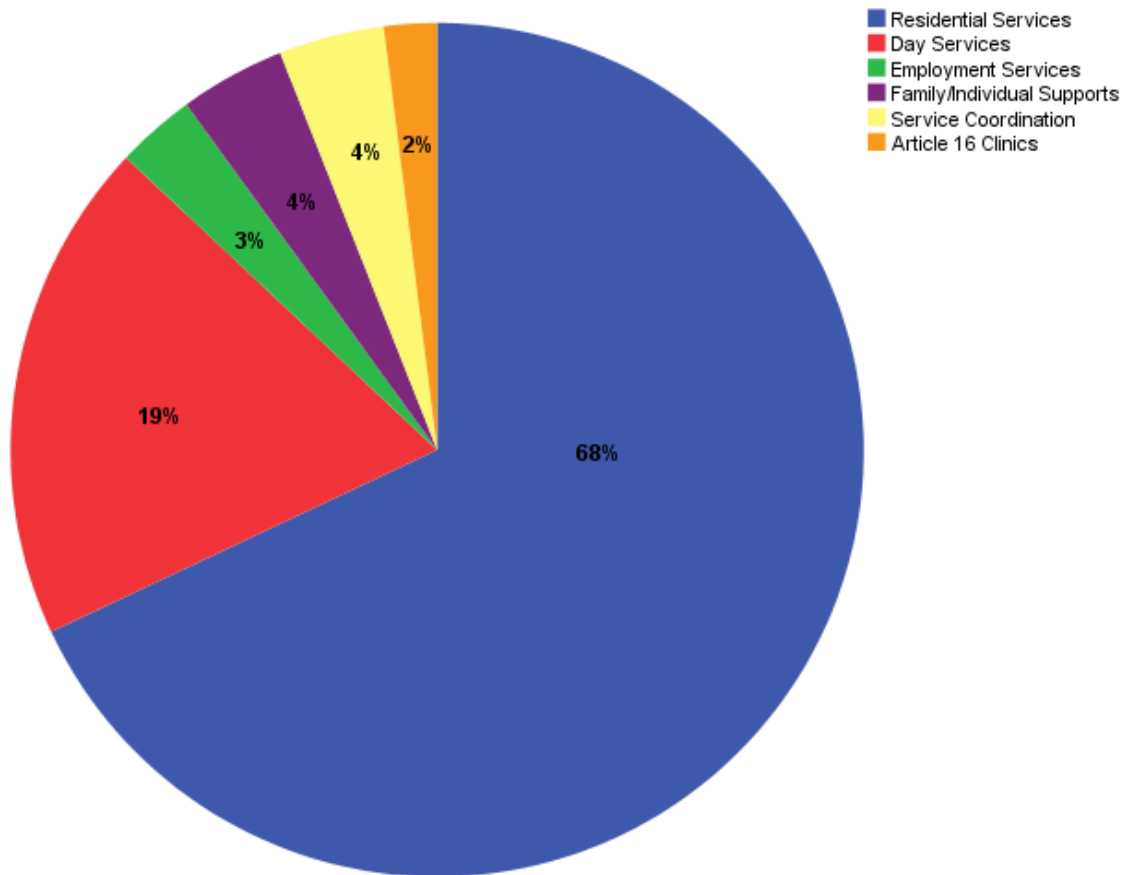
To comply with *Olmstead*, OPWDD will serve individuals in the least restrictive setting that most appropriately meets their needs. Figure 3 illustrates the agency's deinstitutionalization efforts since 1975. By 2011 only 1,313 individuals lived in developmental centers or special units. While this is a commendable achievement, it still remains that some people continue to reside in institutions who could be successful in the community. In addition, funding large institutions for so few people is not fiscally prudent given the budget deficits in NYS. OPWDD's goal is to transition all individuals from developmental centers and maintain about 300 opportunities for specialized units statewide. These opportunities would be for people who temporarily need a more structured environment due to intensive behavioral health needs or forensic involvement.

Figure 3. Institutional Decline, 1975-2011



Finally, the existing administrative and fiscal infrastructure for DD services was designed to be most effective in an institutionally based, congregate care environment with incentives aligned to the development of site-based day and residential programs. Figure 4 shows the distribution of expenditures for community-based OPWDD Medicaid services in state fiscal year (SFY) 2009-10.

Figure 4. Community-based OPWDD Medicaid Spending (SFY 09-10)



The vast majority of these expenditures (87%) were attributed to congregate day and residential programs. The residential services category included Intermediate Care Facilities (ICFs), Community Residences (CRs), Individualized Residential Alternatives (IRAs), and Family Care homes. Day services consisted of individuals in day treatment and day habilitation programs. The remaining 13 percent of expenditures were attributed to more individualized services such as employment, family/individual supports, service coordination, and article 16 clinics. Given the oversized portion of expenditures for congregate-based services, residential and day services will likely play a central role in efforts to contain growth in future year expenditures.

OPWDD wants to perpetuate individualized, person-centered services; however; the outdated infrastructure presents challenges when individuals and families want to develop and implement supports that are tailored to their preferences and needs. With more than 600 voluntary providers, 120 different billing categories, 5,138 different rates, and more than 13.5 million Medicaid transactions each year, the system is unnecessarily complex and difficult to administer. As a result, individuals experience difficulty when trying to access the right service at the right time. To address these types of inequities, funding mechanisms and rate setting methodologies need to be redesigned to offer choice, flexibility and portability.

In summary, OPWDD is facing many new realities about the DD population, as well as environmental factors affecting the health care system in NYS. The People First Waiver will help the State to manage care more efficiently and affordably, providing individuals and families the appropriate level of support.

Stakeholder Involvement

To further develop the 1115 waiver application and conceptualize what managed care means for a DD system, OPWDD engaged stakeholders at every level to promote transparency and open communication during the design process. The People First communications strategy included a dedicated website with up-to-date information about the project, as well as face-to-face interactions with the public to gather feedback through each step of its development. Figure 5 summarizes the timeline for stakeholder involvement.

Figure 5. Timeline for Stakeholder Involvement: Spring-Fall 2011



As a first step, Commissioner Burke traveled to different parts of the state to conduct listening sessions with individuals with developmental disabilities and their families. Approximately 270 people attended the sessions and shared their experiences with the service system. Participants were asked four questions:

- 1) What is working well for you?
- 2) If you could change one thing about the way OPWDD supports you, what would it be?
- 3) How can OPWDD empower people to lead a fulfilling life?
- 4) How can we best determine individuals' needs and allow that understanding to drive the right level of support for that person?

Individuals and families responded with enthusiastic support for self-directed options and family supports:

"My daughter has been in CSS since she was six. I have seen enormous growth in her. It is great not to have to deal with all the agency rules and regulations. It is about her and it is working."



"FSS works well. My sixteen-year-old lives at home. He goes out into the community and we can give time to his siblings."

Some families expressed that the Medicaid rules and regulations can limit the responsiveness of services and supports, and lead to negative consequences for individuals with developmental disabilities:

"Using Medicaid has meant billing for only one service per day so that my daughter needs to take another day for a second type of therapy and cannot go to work another day. This means she has to stay home in a residence where she is the only verbal person. This has caused depression and a need for medication."

The outcomes from the sessions were analyzed and put into a report that is in Appendix A of this document.

Second, OPWDD held formal public forums in New York City, Schenectady and Rochester, and at an additional seven locations via video conference. For people who were unable to participate in one of these sessions, the agency offered an online survey that consisted of the same four questions that formed the basis of testimony at the forums:

- 1) How can we further break down barriers and support people to live truly integrated lives in the community?
- 2) What do families need to better support their loved ones at home?
- 3) What reform ideas do you have to help us operate more efficiently so more funds can be directed to the services and supports people need to be healthy and engaged in meaningful work and activities?
- 4) What should we be measuring to tell us if we are doing a good job supporting people to have good health, positive relationships, live in homes of their choice, and enjoy meaningful activities and employment?

Participant responses (1,199) were summed up into five major categories: Supports and Services, Access and Funding, Quality, Community Inclusion and Public Acceptance, and Individual Control. Many individuals expressed that they want to continue to live in the community, but needed additional supports including respite, transportation, community habilitation, and recreation. One participant said:

"We must provide meaningful and individualized services in the family home, and that will require enhanced staffing for some. This will allow families to take a break and extend their willingness to keep their children at home"

Other forum participants were concerned about individuals with cross-system needs including children, older adults, individuals with autism, those with complex medical needs, and individuals who are dually diagnosed with a developmental disability and mental illness. It was noted that people who need assistance from two or more systems encounter challenges when attempting to access both types of services. Another participant felt that the system should:

"Allow easier access to OPWDD and OMH services at once since there are so many individuals who are dually diagnosed"



Supports and Services

Nearly half of all comments (975) related to Supports and Services. The most frequently cited need was for respite services. People also noted that transportation services, opportunities for recreation and social interaction and community and residential habilitation are extremely important. Concerns about staffing, home, employment and day services, and family supports each generated fewer, but still a substantial number of comments, including calls for greater availability of residential opportunities; praise for the work of direct support professionals; calls for improved wages and career potential for these important workers; calls for greater access to supported employment opportunities, training to prepare for employment and competitive employment and innovative day activities; calls for new family support services and expansion of other types of existing supports.

Access and Funding

The largest number of comments in this category were related to accessing services, followed next by administrative processes, funding, and service coordination. People noted that:

- Accessing services is a complicated and extensive process and a simpler process is needed.
- Services and eligibility should be maintained for people currently receiving services.
- OPWDD should reduce paperwork and streamline administrative processes.
- Service coordination is vital to families, and service coordinators must be well trained and knowledgeable.
- Individuals and families want more control over the funds that are allocated to their services.
- The use of resources should be reviewed to find savings for reinvesting in additional services.

Quality

Well over half the 217 comments related to quality concerned the gathering of feedback from individuals and families, measuring performance and/or improving outcomes for individuals and the quality of services in general. They noted that:

- OPWDD should gauge the effectiveness of the service system by surveying individuals and families on what they need and whether or not their services have met those needs.
- OPWDD should use performance measurements to ensure quality.
- Individuals and families should help determine how the quality of their services is measured.
- Oversight and quality assurance are critical to generating confidence in the system.
- Ensuring safety is critical.

Community Inclusion and Public Acceptance

Of the 214 comments that were related to this topic, 92 concerned community services and integration. Respondents emphasized that the community is the right place for individuals with developmental disabilities. The second most frequently cited comments related to OPWDD's communications and public relations. They told us that:

- For an individual to succeed in the community, he or she must have appropriate support for integration and a community that understands and welcomes them.



- OPWDD should work with public schools to offer sensitivity awareness training and provide public service announcements to convey how valuable individuals with developmental disabilities are to their communities.

Individual Control and Development

The 150 comments received in this category were almost evenly split between those that related to individual and family control and those that spoke to how OPWDD services can support an individual's personal growth.

Respondents noted that they want to be part of deciding who delivers services, as well as where, how and when services are delivered. They also noted they want greater flexibility to adapt these aspects of their services as circumstances in their lives change. Respondents noted that relationships and friendships are the key to personal growth and a meaningful life. Opportunities to socialize and develop these bonds are important.

The feedback provided at the People First Waiver public forums pertained to nearly every aspect of the service system imaginable. Each person approaches the system with different concerns and at a different point in their lives. Yet each requires individualized support delivered in a caring way by professionals specializing in the diverse field of developmental disabilities. Achieving this outcome is the task of the People First Waiver. For a detailed analysis, the report is available in Appendix B of this plan.

Third, a Steering Committee of the People First Waiver was formed to oversee and guide the development of the new waiver and shape the ultimate system reforms the waiver will achieve for NYS. The Committee consists of individuals with developmental disabilities, family members, service providers, public officials, and noted experts in health care and long term care. Two meetings were held, one at the beginning of the design process and one at the end to respond to the recommendations from the design teams.

Fourth, OPWDD established design teams to examine key policy aspects of the developmental disabilities service system and make recommendations to the Steering Committee regarding how NYS can best achieve the goals set out in the waiver concept paper. Design Team membership included self-advocates family members, provider agencies, state officials, and other important stakeholders with specialized knowledge of health and human service systems.

Finally, public hearings will be held in early November. The hearing will provide an opportunity for the DD community and other interested parties to respond to OPWDD's new strategic direction.



Executive Summary

The New York State Office for People with Developmental Disabilities and the New York State Department of Health (DOH) anticipates that in 2012 the federal Centers for Medicare and Medicaid Services (CMS) will grant approval of an 1115 Research and Demonstration Waiver that will be called the People First Waiver and deliver services to individuals with developmental disabilities.

The 1115 reforms articulated in this report stem from the work of the People First Waiver Steering Committee, design teams, and the vast input received from OPWDD's diverse stakeholders. At the heart of these reforms is the strategic redesign of the system of care to better support and facilitate the meaningful outcomes of personal health and safety, positive relationships, work and meaningful activities and access to a desired home setting while incorporating guiding principles of respect for individuals and families, effective care coordination, and realigned incentives.

Once the 1115 waiver is approved by CMS, the reform strategies described in this report will take careful planning, testing through pilot projects, and thoughtful transition and roll out over a period of five to ten years. OPWDD expects to use the first year of the initial five years of the 1115 Waiver Agreement to continue the planning and design work that officially began in Spring 2011.

As you read through this report it is important to remember that the descriptions of desired reforms are meant to outline a vision and a blue print for pursuing that vision over the next five to ten years. As we continue to explore these reforms and the waiver development process continues to unfold, this blue print will adapt and change, but will always stay true to the mission of helping people lead richer lives and OPWDD's guiding principles and core values.

Report Contents

- ✓ Vision for the Future
- ✓ How to Achieve the Vision
- ✓ Realignment and Reform
- ✓ Integrated Care Coordination
- ✓ Flexible Person Centered Services
- ✓ Quality Enhancement



The Purpose of the People First Waiver

OPWDD is pleased to present this report that outlines the proposed reforms to be included in the New York State People First Waiver application to the federal Centers for Medicaid and Medicare Services (CMS) for an 1115 Demonstration Waiver based on the recommendations put forth by the People First Waiver design teams in their final reports.

An 1115 Research and Demonstration waiver is an agreement with CMS that provides states with federal Medicaid funding for services for its citizens, while the state implements changes to its service systems, and then demonstrates the benefits of those changes. Built on a history of state and stakeholder partnership, today's developmental disabilities service system demonstrates what is possible when determined people set their sights on achieving what is right for the people they support. Today, with the People First Waiver, New York is again challenging that same partnership of parents, individuals, service providers, and agency leaders and staff to push beyond current performance, to make a good system even better with improved responsiveness in supports and services, increased person-centeredness, improved personal outcomes and greater transparency and efficiency of operation. The People First Waiver will allow New York to implement important programmatic, administrative, quality, and fiscal reforms that will eliminate the aspects of the system that continue to stand in the way of still greater success for people with developmental disabilities, more effectively supporting each person to live their life to the fullest measure.

As the People First Waiver provides a comprehensive reform initiative that will ensure greater success for people with developmental disabilities and sustainability for the service system, it is important to further advance core principles of respect for individuals and families, quality, choice, and community.

OPWDD will continue to carefully listen to the insights and recommendations of all of our stakeholders as we move forward with this vital initiative which will sustain our system for years to come.

Introduction

The People First (1115) Waiver development process was officially launched in April 2011 when the New York State Office for People with Developmental Disabilities (OPWDD) and the New York State Department of Health (DOH) released a concept paper outlining plans for development of the 1115 waiver. This concept paper highlighted the following key outcomes New York State would demonstrate through a redesigned service system:

- **Improved care coordination** for people with developmental disabilities with complex medical and behavioral health needs can be achieved through specialized systems of care management and coordination.
- A transformed long-term care system that places **person-centered planning, individual responsibility, and self-determination** at the forefront can enhance care and individual satisfaction and lower Medicaid costs.
- **New reimbursement models** for institutional and community-based care systems can encourage efficiency, improve accountability, and reduce costs.
- An **expanded range of community-based services** can allow many individuals currently living in institutional settings to transition to the community such that future institutional services can be provided on a temporary transitional basis to prepare individuals for successful community living.

- **Redesigned assessment tools** and eligibility processes can ensure “no wrong door” access for people who need to access Medicaid services under any State agency.
- Improved health and safety outcomes can be assured through **a transformed comprehensive quality management system that is driven by performance metrics linked to personal outcomes and system performance.**

Also in April 2011, OPWDD Commissioner Burke traveled around the state to meet with individuals with developmental disabilities and family members. These “listening sessions” occurred at seven locations across New York State, and more than 270 people took time out of their day to share their thoughts, concerns, and ideas with Commissioner Burke.

Soon after these listening sessions, OPWDD established the People First Waiver Steering Committee comprised of a wide range of stakeholders, public officials and staff, and noted experts in health care and long-term care to provide high level oversight of a comprehensive planning process that would lead to well informed reform recommendations.

In late May and early June 2011, OPWDD held a series of People First Waiver public forums to gather stakeholder input to help shape system reforms. Sessions were held across the State and via webcast to provide ample opportunity for interested parties to contribute comments. Family members and individuals, agency staff and executives, advocates for people with developmental disabilities, and other stakeholders presented their viewpoints at the forums. In addition, an online survey was conducted, an email address was created to accept submissions of testimony, and written testimony was accepted by mail. A total of 251 submissions of written and spoken testimony and online survey responses were received.

At its first meeting, the Steering Committee chartered five distinct design teams that would explore key aspects of waiver design: access and choice, care coordination, services and benefits, fiscal sustainability, and quality. To ensure broad participation, these design teams were comprised of people with developmental disabilities, parents and family members, provider agency staff, experts in health/long-term care, and other stakeholders. They began their work with a Kick-off meeting on June 20, 2011. Over the course of the summer months, the design teams met to research, discuss and make recommendations related to key areas of service design and delivery, funding and system administration. Their work culminated in September 2011 with a report of recommendations from each design team to the Steering Committee.

A Shared Vision for the New Service Delivery System

“Vision” can be defined and understood as follows:

- A realistic, credible, and attractive future for an organization (or system). It is a mental model of a future world that cannot be observed or verified in advance and that, in fact, may never become reality; however, it shows the way to identify goals and how to plan to achieve them. The vision must be realistic enough so that people believe it is achievable but idealistic enough so that it cannot be achieved without stretching (Burt Nanus).
- Vision should describe a set of ideals and priorities, a picture of the future, a sense of what makes an organization/system special and unique, a core set of principles that the organization/system stands for, and a broad set of compelling criteria that will help define organizational/system success in getting there (Oren Harari).



The input and feedback from all of the Steering Committee, the design teams and OPWDD's public outreach confirm that the people OPWDD serves have a wide range of service interests and needs. However, these efforts also confirmed that, despite these differences, our stakeholders largely agree on issues of concern and needed service system improvements. Through this process, a shared vision for a sustainable and improved developmental disabilities service system has begun to emerge. This report, which synthesizes, consolidates and builds on the collective input and recommendations of the Steering Committee, design teams, and our vast array of stakeholders, is the first step in articulating that vision so that it can inform and direct the process of redesigning our service system for a sustainable future.

OPWDD anticipates CMS approval to proceed with the 1115 Waiver in 2012. The CMS approval authorizes OPWDD to pursue this shared vision—this realistic, credible and attractive future based on the ideals and priorities of our stakeholders—and bring it to fruition over the next five to ten years.

The Vision

While the design process for the People First Waiver gave voice to a shared vision for service system improvement, it also confirmed OPWDD's current vision and core values as a solid guiding foundation for all we do:

That all people with developmental disabilities will enjoy meaningful relationships with friends, family and others in their lives, experience personal health and growth, live in a home of their choice, and fully participate in their communities.

The changes brought by the People First Waiver will add operational detail and evidence to demonstrate the goals of the waiver set forth in the concept paper. The fundamental hypothesis New York State will put forth to the federal government is that through comprehensive care coordination across systems, more flexible and innovative community service and support options and new and enhanced community supports for people with complex needs and/or behavioral challenges, New York State can effectively support people with developmental disabilities in less restrictive settings for longer periods of time and transition people who reside in more restrictive settings to less structured and more flexible every day settings in the community, and ultimately, that these improvements will result in enhanced satisfaction and quality of life for the people we serve.

*These reform proposals
reflect shared vision—a
realistic, credible and
attractive future based
on the ideals and
priorities of our
stakeholders.*

To this foundational vision and initial waiver hypothesis, the process of waiver design described above added the following expansion and refinement:

- Person-centered principles, individualized outcomes, and the utmost respect for individuals and families will be the driving force in the service system.
- Individuals with developmental disabilities who need to access Medicaid services from multiple state agencies will face no wrong door, enabling people to approach any agency for comprehensive services that will make the system more people and family friendly.



- There will be comprehensive and integrated coordination of care for individuals across all life domains including health, behavioral health, clinical needs, and other long-term care services that will help an individual to receive all supports he or she needs to live as independently as possible.
- There will be greater access, choice, and flexibility in service delivery that will allow services to better respond to individuals' needs with appropriate, individualized levels of care.
- People with high levels of behavioral needs will receive responsive services in community-based settings. Through effective care coordination and the enhancement of systems in place for individuals who have significant interfering behavior, services will be provided across a broad variety of community-based settings with emphasis on ensuring the least restrictive setting possible.
- The need for institutional-based services will be reduced as there will be an enhanced system of community support services designed to address the complexities of individual needs in community-based settings. Institutions will provide short-term stabilization, assessment and transition services to prepare individuals for community-based settings.
- There will be rational, equitable, and efficient financial resource distribution based primarily on individual needs rather than historic program costs.
- There will be appropriate financial incentives so that funds are more clearly tied to services and supports that individuals need and the positive outcomes they desire.
- There will be a comprehensive method to measure service outcomes for people with developmental disabilities. Metrics will be used to confirm how the individual is doing, individual satisfaction, as well as how responsive the system is as a whole. Quality metrics will be used to guide policy and fiscal decisions; promote and reward excellence in service delivery; improve efficiency and effectiveness of state quality management resources; and guide enforcement actions when program and/or fiscal compliance is breached.

So What Does This Vision Really Mean?

To understand what this vision will look like and what changes it will bring, it is helpful to ask three critical questions:

- (1) What is expected to remain the same?
- (2) What is expected to change for individuals receiving services and family members?
- (3) What is expected to change for providers?

What do we expect to remain the same?

As the mission and foundational vision for supporting individuals with developmental disabilities will remain secure, much of what the current service system provides will also remain the same:



- OPWDD will continue to be the state agency responsible for overseeing the system of supports and services for people with developmental disabilities.
- The definition of developmental disability, as outlined in the Mental Hygiene Law, will not change.
- Protecting the health, safety, and rights of people with developmental disabilities will continue to be of paramount concern and importance, and will still be a central focus of the service delivery system.
- Our service providers have been and will continue to be the foundational structure of the new service delivery system. Quality not-for-profit agencies with experience and expertise working with people with developmental disabilities will continue to operate in the service delivery system and will be the basis for new entities that will be developed to take on a central role in care coordination for individuals with developmental disabilities.
- The types of services and supports that people receive today will still be available, although they may be defined, delivered, and financed differently.
- Comprehensive residential services (with 24/7 care) will be available for those who need that level of care.
- There will continue to be self-directed service options that will allow individuals to hire their own staff and direct and make choices on an individualized budget. To do so, OPWDD will build on the best outcomes of the self-direction option Consolidated Supports and Services, but simplify and make this option more broadly accessible.
- OPWDD will continue to make strides in ensuring that Direct Support Professionals (DSPs) have the competencies, training, tools and support that they need to deliver quality services as well as opportunities for growth through a real career path and compensation that truly reflects the critical importance of this workforce to people with developmental disabilities.
- As we retool the types of services provided and develop new processes of coordinating and paying for these supports, OPWDD will continue to work to ensure continuity of care for individuals and families and avoid abrupt and disruptive transitions.
- OPWDD will continue to communicate openly and continuously and work collaboratively with all of our stakeholders as changes unfold over the next five to ten years.

What do we expect to be different for individuals?

Over the next few years, as the reforms of the People First Waiver take shape through implementation planning and pilot projects, the following changes will occur:

- Person-centered service plans will be based on assessment tools that are strengths-based and support informed choice. These plans will describe comprehensive care and determine equitable resource allocation across the population.



- Through consistent individualized needs assessment and care planning, plans of care will be implemented across a broader array of living options. For individuals who have gained skills and/or are seeking greater independence, comprehensive care coordination will deliver more flexible and responsive service options that better meet individuals' unique needs, and lower costs.
- There will be updated and improved ways to assess individuals' needs so that we appropriately provide greater levels of service to those with greater needs. This could mean changes for some as individuals move into less restrictive settings and begin to enjoy more inclusive and meaningful lives. For others it will mean confirmation of their need for close supervision and support.
- The waiver framework will enable more flexible funding of staff supports for individuals so that they can seamlessly go from paid employment to volunteer opportunities, prevocational opportunities, community habilitation, etc.
- Greater flexibility and individual choice in where, when, and how services are delivered.
- Access to needed supports across other service systems including behavioral health, health, and personal care, with care management monitoring to ensure adequacy and best practice planning approaches.
- As resources are better managed, the expectation is that the more restrictive and higher cost options will be avoided through proactive treatment strategies, and people will utilize the more restrictive and higher cost options only when needed and only for as long as the option is needed.
- Self-directed service options will be simpler and easier to access and navigate. A continuum of options including budget authority (authority to make choices and direct an individualized budget) and employer authority (authority to select and manage one's own staff) will be available to all.
- Individuals will be able to self-hire neighbors, relatives, friends, and others, in their communities with whom they have relationships to provide care and supports.

What do we expect to be different for providers?

Service providers can expect the following operational changes:

- How services are financed and paid for will be different. Rather than funding providers' "programs" and levels of service through "fee-for-service" billing arrangements that may not necessarily support needs and goal achievement, there will be increased precision in how services are financed and targeted to meet peoples' needs, bringing greater equity in the availability of services throughout New York State.
- Through a care management capitated funding structure, the broadening of service categories, and development of innovative community support options for complex needs, providers will be better

able to target innovative and person-centered services and the ways they are delivered to respond to individual needs and interests.

- “No Wrong Door” strategies will make it easier and quicker for individuals to access and receive supports and services across all Medicaid service systems.
- There will be a team oriented approach to care coordination to ensure that there is knowledge and expertise in all the identified areas of need for an individual. Care Coordination will build on the strengths of Medicaid Service Coordination (MSC), but will ultimately include coordination of health-related services as well as OPWDD services and services offered through other state agencies and community resources. Care coordination will focus on helping an individual to meet their personal outcomes.
- Quality will be measured consistently across all settings in ways that align with the established mission, vision, values, and guiding principles of OPWDD. Quality assessments will measure meaningful indicators related to individuals’ personal outcomes as well as the manner in which care coordination entities are operated, managed and governed, and services are planned and delivered.
- A transparent quality rating system will be established based on clearly articulated standards; each provider’s rating will be publically available to those seeking supports.

Achieving the Vision

Today’s Infrastructure

Infrastructure is the underlying foundation, features and components of a system. In the system of supports and services for people with developmental disabilities, the fiscal and administrative infrastructure exists in the organizations that support and facilitate the delivery of supports and services to individuals.

Our infrastructure today includes services and various funding streams; the paths of funding different kinds of services, service fees, reimbursement methodologies and rates; provider organizations, information management technologies; quality systems, regulations and policy statements that describe how things are organized, administered, managed, and evaluated to achieve the mission of helping people live richer lives.

The foundation of today’s organizational infrastructure is the 600-plus not-for-profit providers that deliver a menu of long-term supports and services that are primarily habilitative to people with developmental disabilities and bill Medicaid directly through a fee-for-service system. Some of these providers operate certified Intermediate Care Facilities (ICFs) and/or certified individualized Residential Alternatives (IRAs) where people with developmental disabilities reside. Some also operate clinics that deliver certain clinical services from the predefined menu of allowable clinical supports. Programs and services operated by these

providers are certified and reviewed by OPWDD through its Division of Quality Management and regional Developmental Disabilities Services Offices (DDSOs) according to regulation.

Over time, our system has become more complex and more difficult to administer. The present infrastructure results in documentation of approximately 120 different billing categories, 5,138 different reimbursement rates, and more than 13.5 million Medicaid transactions annually for OPWDD's population alone. This situation demonstrates clearly the need for more cost-effective and sustainable approaches to meet OPWDD's mission in the future.

System Reform: Creating a new Fiscal, Administrative & Organizational Infrastructure

The specific reforms that will help us achieve our shared vision for the developmental disability service system over the next five to ten years include the following:

- Reformed Care Management that Realigns the Infrastructure for Improved Sustainability and Outcomes
- Provision of Integrated, Comprehensive Care Coordination within the Care Management Infrastructure
- Improved Home and Community-based Services with a Broader Menu of Community-based Clinical/Behavioral and Crisis Services
- Administrative efficiencies and enhanced Quality Infrastructure

The goal of care management is to improve coordination of care while providing cost-effective non-duplicative services and to focus attention on the whole person instead of only certain aspects of the person.

Reformed Care Management

Over the next five years, the People First Waiver will transition our current system of developmental disabilities services to one that provides integrated and comprehensive care management. The term "care management" as articulated by the New York State Medicaid Redesign Team (MRT) refers to the application of systems, science, incentives, and information to deliver care that best meets individuals' comprehensive physical, behavioral, and social support needs effectively. The goal of care management is to improve coordination of care while providing cost-effective, non-duplicative services and to focus attention on the whole person instead of only certain aspects of the person.

Under the People First Waiver, the function of care management will be the responsibility of not-for profit organizations that have experience and expertise providing supports and services to people with developmental disabilities and that demonstrate the fiscal, quality and person-centered competencies necessary to perform care management effectively. The not-for-profit organizations that are authorized by OPWDD to perform care management responsibilities will be called Developmental Disabilities Individual Support and Care Coordination Organizations (DISCOs). These DISCOs will be the organizational foundation of our new service system.

Each person with developmental disabilities in the waiver will have a choice between at least two DISCOs to provide their comprehensive care management. Within the care management infrastructure each DISCO will be responsible to perform at least two primary roles for the people it serves: a) care coordinator and b) fiscal intermediary. Each DISCO will be responsible for delivering care to the enrolled individuals, by providing the services directly to individuals and/or by contracting with a diverse and culturally competent group of providers across systems to deliver comprehensive services.

In its care coordination role, the DISCO will facilitate co-management and information sharing between all services and supports currently funded through Medicaid. Care coordinators will facilitate and coordinate delivery of services from across different service systems, as well as community and other natural supports for the person. These services include traditional health care services, NYS Office for People With Developmental Disabilities (OPWDD) services and other specialized care, e.g., mental health, long-term care and substance abuse services. The care coordination role of the DISCO is described more fully in the next section and is a fundamental reform and major building block of the new service system.

In its fiscal intermediary role, the DISCO will receive a monthly capitation payment to fund all Medicaid covered services and coordinate non-Medicaid services identified in the individuals' service plans. The capitation payment will be derived from one or more independently administered needs assessment tool(s) and augmented by necessary adjustments. A "capitation" payment is a fixed dollar amount provided for a service recipient regardless of the amount of services/treatment that person receives during the time period of the capitated payment. Capitated payments are usually based upon the abilities and needs of the individuals served, taking into account various factors such as functional and cognitive status, diagnoses, demographics or other measures found to be correlated to increased costs of services. Capitated payments will be sufficient to support the provision of covered long-term care services, care coordination, and primary medical, dental and acute care.

In our current infrastructure, fee-for-service is the primary payment methodology. In this method, providers receive a fee or rate for each unit of service delivered to a person. OPWDD believes that modernizing our infrastructure to a care management structure with a capitated payment methodology derived from each individual's valid needs assessment will enable the administrative, fiscal and organizational changes necessary to make the People First Waiver vision a reality.

Specifically, the new care management platform (as opposed to the current fee-for-service system) will:

- Modernize reimbursement and the flow of funds so that DISCOs will receive a known and predictable revenue stream (capitation rate) for each individual served. Using this predictable amount, the DISCO can work with an individual and their circle of support to design a comprehensive package of supports and services that best meet the person's specific interests and needs. In this way, the system compensates providers for delivering on individual needs, goals and outcomes, rather than on the delivery of staff actions and historic program costs tied to facilities and buildings. The modernized reimbursement structure also supports innovation in the deployment of staffing and supports, enabling greater creativity in individualized service provision;
- Provide payment to DISCOs that reflect the needs of individuals so that there is no disincentive to serving individuals with high needs, encourage appropriate service options that result in higher levels of satisfaction for people and often at lower cost, and enhance the focus on more preventative measures that avert crisis situations, which typically drive up costs;

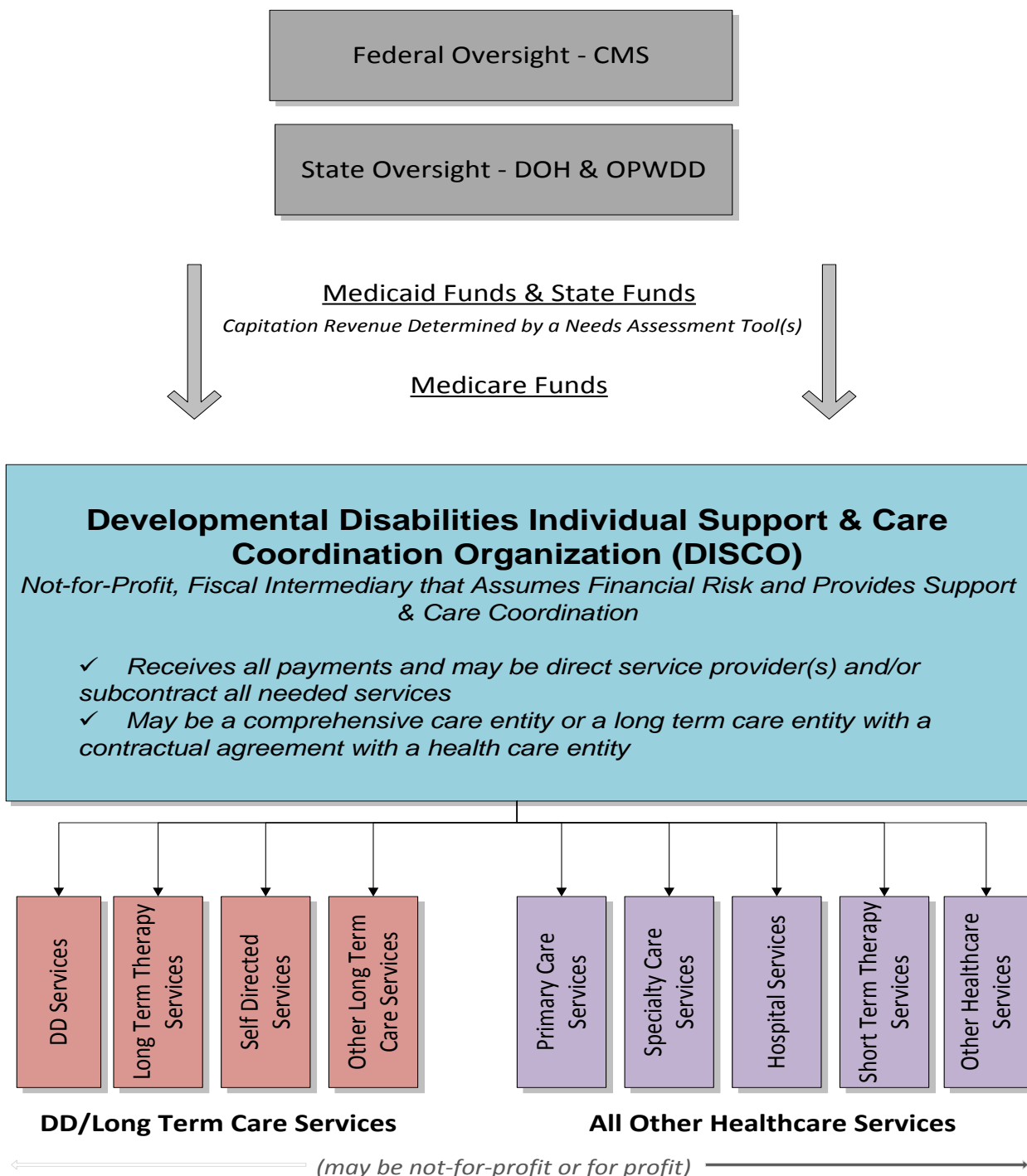
- Facilitate the maximum use of natural supports and community resources and maximize the use of the least restrictive settings; promote employment support, delivery of services in every day community settings over traditional site-based day habilitation programs, and self-directed service options;
- Shift from a fee-for-service system to a capitation rate system to allow service providers to focus resources less on certain documentation and billing compliance activities and more on person-centered planning, service delivery and personal outcomes.
- Better position New York State to take advantage of national trends in integrated health care including opportunities for better coordination of Medicare and Medicaid funds.

The proposed platform is designed to be flexible and will support a variety of operational models including a model where the DISCO is solely the fiscal intermediary and care coordinator and reimburses subcontractors through contracts, sub-capitation or other arrangements for all services that are provided to the individuals the DISCO serves. Alternatively, the DISCO could be the fiscal intermediary, the care coordinator, and a direct provider of certain services, (e.g., habilitation employment, long-term therapeutic services, etc.) and would reimburse providers of other needed services through similar contracting arrangements detailed above. Over time the DISCO will assume full financial risk for meeting each person's service needs within its capitation revenue. Initially, there will be some form of "risk mitigation strategy" in place while these entities gain experience in operating in a risk environment. Strategies may include risk-sharing with New York State or the establishment of "risk corridors."

The shift from a fee-for-service system to a capitation rate system will allow service providers to focus resources less on certain compliance activities and more on person centered planning, person centered service delivery, and personal outcomes.

OPWDD will monitor DISCO care management performance through contract requirements and quality review procedures. Contract requirements will include provisions that require DISCOs to offer a continuum of self-directed service options as well as a full contingent of services and support options to address needs across all life domains (primary health, behavioral health, habilitation, etc.). Subcontractor diversity and cultural competency will be key quality indicators. Additional quality indicators may include, but are not limited to, the demonstrated flexibility to change supports and services as individuals' needs change, engagement of individuals and families in all aspects of DISCO operations and oversight, the frequency of out-of-network service use, the capacity to accommodate growth, response time for initial and follow-up services; and the quality and competency of each DISCO's workforce and contractors including the availability of providers to deliver specialized care, services for those in geographically remote areas, and to operate with appropriate cultural competency.

Figure 6. People First Waiver Fiscal, Administrative and Organizational Infrastructure



Providing Integrated Comprehensive Care Coordination within the Care Management Infrastructure

Another major building block for the 1115 waiver is to design and implement comprehensive care coordination. As discussed above, the role of care coordinator is a primary function of the DISCO within its care management role. The DISCO may perform care coordination directly or subcontract with a provider that meets OPWDD requirements to perform care coordination.

OPWDD defines comprehensive care coordination as a person-centered, interdisciplinary approach to addressing the full range of a person's needs, integrating habilitation, medical and behavioral health care, and support services. In this process:

- (1) A comprehensive care plan is developed based upon a standardized needs assessment that identifies the person's strengths, needs, and preferences, and
- (2) Services are managed and monitored by an identified care management organization, i.e., a DISCO.

Individualized and person-centered approaches will be used to coordinate care for every person with a developmental disability enrolled in the 1115 waiver.

Formal and standardized needs assessment tools and ongoing needs assessment processes regarding support and treatment needs will help to inform the development of each individual's comprehensive care plan based on the individual's assessed strengths, needs, interests, health status, functional status, and desired personal outcomes. Determining how best to meet each individual's identified needs will employ an integrated approach, involving the consultation of professionals with different expertise and reviewing the full range of community, family and service supports. The care plan will incorporate benchmarks to assess the progress the individual makes over time, and regular review and revision of the care plan will be incorporated into the care coordination process.

To ensure that the plan is comprehensive and effective, each individual will have access to a core care coordination team with a designated team lead that has experience and expertise in working with people with developmental disabilities. The DISCO will recruit and hire a panel of professionals with different expertise and specialty backgrounds (e.g., nurse, education specialist, employment expert, clinicians, etc.) and knowledge of local cross systems resources in the person's geographic area. These professionals will be available to participate on care coordination teams as dictated by individuals' care plans so that an expert can assist the care coordination team lead in addressing all of an individual's identified needs effectively. Individuals will have access to care coordination whenever it is needed including outside of regular business hours.

In addition, the DISCO will have procedures and methodologies in place to assist care coordinators in finding and developing neighborhood resources and will complete outreach to other systems

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and behavioral health
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services.*



such as the New York State Office of Mental Health, the New York State Education Department and the New York State Department of Health's Early Intervention Program. This will ensure that there is continuity of care, that services are integrated within and across systems, and that services are non-duplicative.

The DISCO will operate according to the values and guiding principles of the OPWDD system. Some of these principles include providing opportunities for self-direction and self-determination, utilizing natural supports, and providing choice. The DISCO will employ true person-centered planning methodologies as embodied in policies, guidelines, and tools to articulate outcomes agreed to by the individual that reflect individualized interests and choices.

The new care coordination model will enhance individual and system outcomes by:

- Using true person-centered tools and methodologies that will help drive individual outcome achievement;
- Using a team approach to care coordination that will ensure the individual has access to the right level of expertise at the right time;
- Ensuring that care coordination professionals are adequately educated and trained, and exhibit the necessary competencies to perform the function;
- Providing care coordinators with strengths-based needs assessment tools and strategies that will help them to effectively coordinate the right level of supports and services for each person;
- Minimizing the fragmentation of cross system services that exists today by giving DISCOs ultimate responsibility to ensure that each person's full range of needs are met through an integrated team approach; and
- Defining broader service categories that support greater flexibility in where, when and how services are arranged for and delivered.

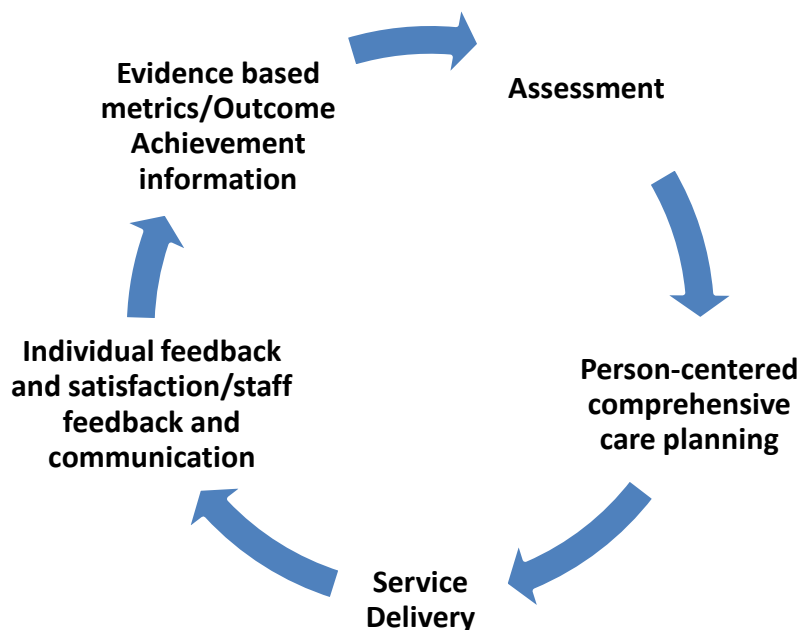
To fulfill the People First Waiver vision, the care coordination and services system must move from one that operates within program silos to one that provides supports and services seamlessly to support all aspects of a person's life.

The operations of DISCOs and their staff will be reviewed to ensure that they adhere to OPWDD's values and guiding principles and that individuals' outcomes are being met. As the plan of care will be developed based on the assessed needs and strengths of each individual and the family unit, the quality review will ensure that the care plan is appropriately derived from sound assessment strategies. Quality measures will include the DISCO's ability to access and utilize natural supports, offer and implement self-direction/self-determination for individuals, and the policies and procedures that are in place to address an individual's complaints, grievances, and changing needs. Quality outcomes may be gathered through surveys, with the results of these surveys made transparent to individuals and families. Measurable benchmarks developed at the assessment and Level of Need determination and the resulting care planning process will support the tracking of personal outcomes.

To fulfill the People First Waiver vision, the care coordination and services system must move from one that operates within program silos to one that provides supports and services seamlessly to support all aspects of a person's life. The questions asked by care coordinators should never be, "What programs do we place this person in?" but rather, "What supports does this person need to

achieve his or her goals?" The system should then have sufficient flexibility to build these needed supports around the person including services that cross existing service system "silos."

Figure 7. The Integrated Care Coordination Cycle



Restructuring Home and Community-Based Services

In today's system specific services are broken down by program and funding source which makes it more difficult to focus on the whole person and integrate services across funding sources and systems. As a result of these "silos" in program and funding structures, methods of service delivery tend to focus on distinct segments of a person's day rather than on the person's abilities across all aspects of his or her life. In addition, today's system still relies heavily on group home models that were first developed over 20 years ago, and little has changed in the infrastructure of these service models since their inception. New York has been slow to develop individualized and self-directed service options that are the core of many other state service systems. We have not fully explored opportunities for shared living arrangements, family care and support, and other more flexible and less costly models that now characterize service menus in other states. Together, these factors contribute to a broad range of service options that work well for some people, but do not work well for others. Some stakeholders have characterized this dichotomy as providing either the high end service package (if in 24-hour supervised setting) or "next to nothing" (if the individual happens to live at home). As a result, obtaining and retaining a group home placement has become the end goal for many families.

While site-based residential and day facilities work well for some people and will remain an option in our service system, we must build a broader menu of community integrated supports to offer more choice, flexibility and integration opportunities for individuals who do not need or want the highly structured, site-based program models. Under the People First Waiver, New York State will develop a broader range of



community-based service options that can meet the needs of individuals at different levels and times in their lives and often at lower cost.

The People First Waiver will enable real person-centered planning to thrive because the financing of supports and services will no longer be based on where an individual lives or where they go to receive services (e.g., a site-based day habilitation program). Instead, financing will be tied to the person's strengths and needs determined through a valid needs assessment process that will inform a resource allocation methodology. This, in turn, will provide a fixed payment to the DISCO on behalf of the person. Through care coordination and person-centered planning, the DISCO will help the person to develop a life plan and will finance that plan. An individual will be able to choose self-direction opportunities and may change DISCOs if he or she is not satisfied.

The People First Waiver services and benefits package will build upon what works well, while integrating service options that bring the system to a higher level of quality, individual satisfaction, and personal outcome achievement, often at a lower cost.

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lower cost.*

To accomplish these goals, the People First Waiver benefit package will offer:

- Real and ongoing person-centered planning for all enrollees;
- A broader array of support options to choose from to more effectively and efficiently meet individual needs and interests in the most appropriate and least restrictive community settings;
- Support for people who are or want to be employed;
- Promotion of lifelong learning and movement so that supports can be diminished as people gain independence;
- Emphasis on citizenship and volunteerism through inclusion and full participation in the community;
- A continuum of self-directed service options that allows individuals to choose how much and what level of control and responsibility they want;
- Supports for challenging behaviors;
- Flexible financing options for individuals who reside in non-certified settings with or without family members (i.e., shared living);
- Access to technological innovations that can enable more independent living;
- The right level of service, delivered at the right time and in the most appropriate community setting; and
- Informed choice and independent advocacy.

1115 Waiver Services

The People First Waiver will deliver supports and services that respond in a person-centered way to each individual's unique identified needs. To make this greater individualization possible, it will describe the kinds

of services available in broad terms, allowing for greater flexibility in shaping service plans to each person's interests, needs, abilities and available natural supports. The People First Waiver will adopt a construct of four broad categories of support as follows.

Family and Individual Support, Integration, and Community Habilitation

This category will include habilitation supports (defined as services that are provided to assist an individual to acquire and retain a variety of skills including self-help, socialization, and adaptive skills), employment related supports (including career counseling, supported employment, job coaching), and respite services for family members and caregivers. With this broad service category, habilitation and other supports can uniquely support individuals to achieve their defined personal outcomes rather than requiring each person's goals and outcomes to be shaped by the location of service delivery. Family and individual support, integration and community habilitation services will be able to be delivered in any setting, including the person's own home, certified homes and other locations, shared housing and everyday community settings. Individuals will have the ability to self-hire neighbors, relatives and others to provide support if they choose. Under this category, individualized approaches to employment supports can blend the habilitative, prevocational, and supported employment approaches that are necessary to deliver on employment outcomes based on the strengths and capacities of each person.

Flexible Goods and Services

This category will encompass a broad range of goods and services that will be available based on the needs and choices of the individual and the family unit. This category may also include family stipends. In general, this category will include goods and services that address needs identified in the service plan, decrease the need for other more costly Medicaid services, and/or promote community inclusion and/or health and safety. This may include purchasing assistive technologies and smart home supports, environmental modifications, support services, recreational activities, and other purchases that contribute to meaningful outcomes. This category may also include the purchase of goods and services necessary to set up a residence if an individual is moving from a group home setting to their own apartment or a shared living arrangement.

This category will also include more streamlined and simplified self-directed service options including individual self-directed budgets and the ability to self-hire relatives, neighbors, friends, and others to provide specific supports as defined by the person and his or her circle of support. During Commissioner Burke's listening sessions with individuals and family members and the People First Waiver public forums, individuals and family members made it clear that self-direction has made a significant difference in people's lives, but must be streamlined and expanded to allow more people to choose and direct their services. Providing individuals and families with choice and control is a primary means of respecting their rights and dignity, one of the guiding principles of the People First Waiver. Enhancing opportunities for individuals to exert choice and control over their

Within the category of Flexible Goods and Services, the option to self-direct one's services and budgets will continue, with improved administrative processes that will make this service option workable and fulfilling for more people.



services is therefore an important objective of the waiver design. Within the category of Flexible Goods and Services, the option to self-direct one's services and budgets will continue, with improved administrative processes that will make this service option workable and fulfilling for more people.

Home and Community-Based Clinical and Behavioral Supports

As individuals leave state-operated institutional settings the need for coordinated clinical supports and enhanced access to cross system services is imperative to ensure they are successful in community-based settings. Similarly, clinical and cross system supports must expand to more effectively meet the needs of others who live at home or in less restrictive settings.

This category of People First Waiver services will include all clinical services currently provided to people with developmental disabilities through the Medicaid State Plan and/or through Article 16 and Article 28 clinics. Services in this category will be provided in homes, community-based settings, clinic settings, offices, and other every-day community settings. Behavioral supports and services will be more easily accessible and responsive to the needs of a broad range of individuals: adults living or seeking to live independently; children and young adults supported within the context of their family; those in intermittent crises; and those with ongoing challenges of interfering behavior and related support needs. Supports will be delivered according to identified need regardless of an individual's living setting and level of complexity. The effectiveness of the supports will be measured based on the outcome for the person, not on the delivery of the service.

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settings.*

Through the People First Waiver OPWDD will work with its stakeholders to develop the expanded capacity needed to provide appropriate behavioral and medical supports to more people in community settings. Specifically, we will increase staff training, family education, interdisciplinary clinical support, and enhanced staffing supports. OPWDD will work to ensure that these supports are available with appropriate clinical monitoring through the care coordination process. The need for true person-centered planning is especially important for people who have complex needs.

The OPWDD system of supports requires knowledgeable clinicians with an understanding of the unique nature and individual intricacies for people with developmental disabilities. NYS will strive to improve our clinical support models to ensure the highest quality provision of supports by establishing and fostering connections with universities for research, support, and development of best treatment/support practices.

The following areas will require increased focus as OPWDD, in partnership with its stakeholders, redesigns the system of clinical and behavioral supports to better meet the needs of individuals:

- Behavioral supports that are evidence-based, integrated and responsive;
- Crisis supports to stabilize the person, and where relevant, the family, thus avoiding more restrictive and costly placements;

- Individual and group counseling focused on relapse prevention, anger management and evidence-based therapy models;
- Behavioral health/psychiatric treatment; and
- Effective therapies such as physical, occupational, and speech.

Using the comprehensive care coordination model, the provision of effective clinical supports that meet identified needs will support individuals to live in the least restrictive environment possible.

Health, Medical and Dental Services

All services currently delivered under the Medicaid State Plan to people with developmental disabilities, such as comprehensive primary medical and acute care services, podiatry, dental services, and other specialty medical services, will be financed through the People First Waiver. The capitated payment model through comprehensive care coordination and care management will provide the incentives for provision of a greater degree of preventative care to individuals that will result in better outcomes and lower costs.

Figure 8. The People First Waiver Service Delivery Infrastructure

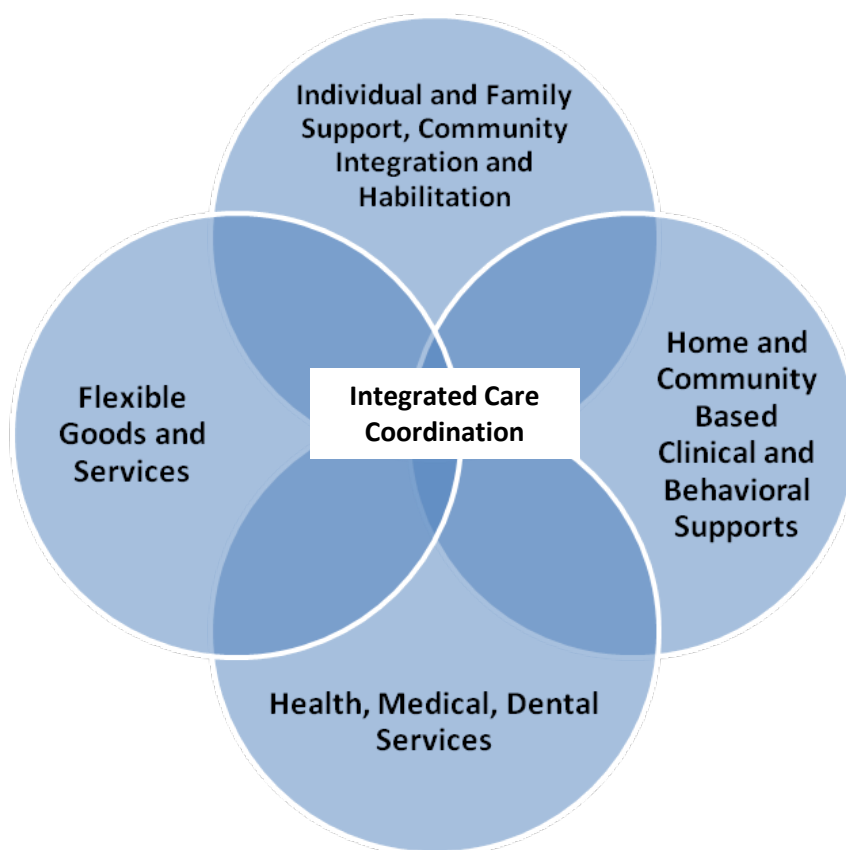
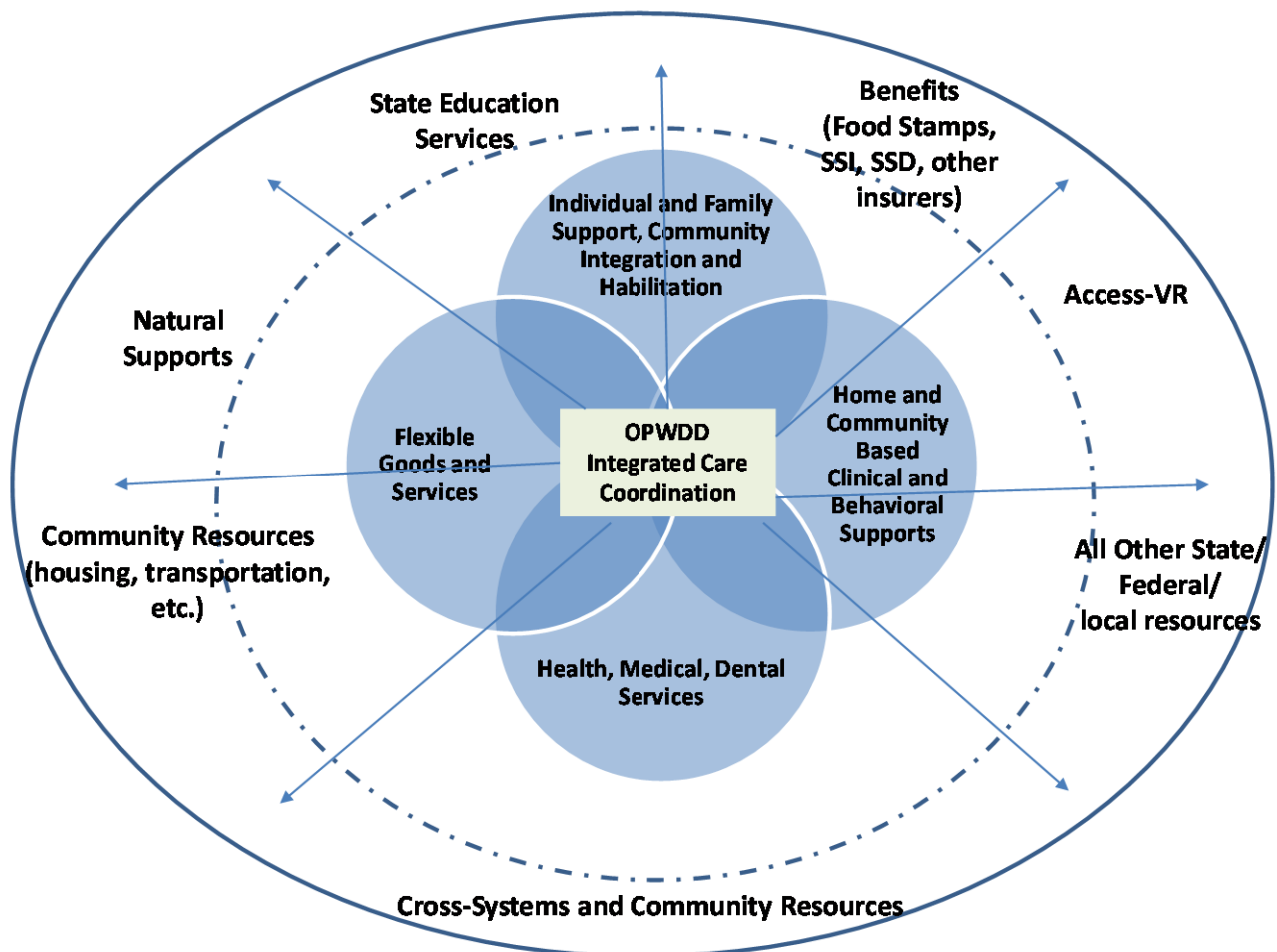


Figure 9. The People First Waiver Service Delivery Infrastructure and Integrated Care Coordination



Fostering Innovation

Based on the improvements to the system infrastructure, comprehensive care coordination and more flexible financing and supports, DISCOs, together with the people they serve, their provider networks, and communities, will have greater flexibility to innovate new options for supporting people. For example, the KeyRing Model of Support currently being demonstrated in England is based on people living in their own homes, but sharing their skills and talents with each other and with the communities. There is a volunteer in each network who, like a good neighbor, will help out if difficulties arise. Because the volunteer lives in the community, he or she knows what is going on and is able to help members make connections to the assistance they need. There are also community support workers and supported living managers who make sure that members get the support they need. KeyRing asserts that community connections are very important and encourages people with developmental disabilities to make good links within their neighborhoods.

Another innovation could be DISCOs facilitating and promoting the opportunity for Direct Support Professionals and others in the workforce and the community to foster shared living environments with people served by the DISCO.

A third example of an innovative model that DISCOs could foster is the College Experience model that was created through OPWDD's Options for People Through Services (OPTS) through a partnership with the College of Saint Rose in Albany and a provider organization. This program is only one of a handful of academic programs in the country serving people with developmental disabilities over the age of 21. In this type of model, students have the opportunity to attend college with the goal of transitioning to adult life through accommodated instruction that addresses students' needs for practical life, social, and work skills. Through shared living and the college experience, students become increasingly independent and capable members of the community, determine their own goals, participate in campus life, and receive an excellent foundation for life after graduation.

Encouraging Innovation in Residential Options

Through greater flexibility in services, staffing supports, and flexible funding options, the People First Waiver can help expand the use of assistive technologies, smart home supports, environmental modifications, shared living opportunities and other innovations to enable more individuals to successfully choose community integrated residential living.

Creating partnerships with organizations in the broader community in areas such as affordable housing and other community resources can further promote creative residential options for people with developmental disabilities.

These examples showcase just a few possibilities among a wide range of possible innovative designs. Through the capitated payment model that has built in incentives for preventative care and lower cost options coupled with new flexible funding opportunities, 1115 waiver tools, and the passion and commitment of our stakeholders, innovative models should be able to grow and thrive.

Enhancing and Aligning the Quality Infrastructure

Quality means different things to different people. In health care, the Institute of Medicine defines quality as doing the right thing at the right time and in the right way, noting that there needs to be a balance between overuse, underuse, or misuse of health care resources. OPWDD sees quality as both objective and personal, aligned in two clear tracks—quality of life and health and safety. Both of these tracks need to be measured and reviewed at both the individual level and the system level and together provide the basis for designing quality improvement initiatives that help people lead richer lives. While the health and safety of the people we serve is of paramount concern and importance, it is not in and of itself enough to help people lead richer lives.

As the primary outcome of OPWDD's service system is a richer life for those served, the People First Waiver will integrate quality of life indicators into our system and create procedures that allow us to use quality measures to continually enhance and improve our ability to deliver on OPWDD's mission, vision, values and guiding principles. As the service delivery system transitions to provide broader and more flexible and person-centered supports coupled with integrated care coordination across systems, OPWDD will be able to develop and employ performance metrics that relate to personal outcomes and quality of life.

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As we do this, OPWDD will be able to use the new 1115 administrative, fiscal and organizational infrastructure to design quality review methodologies that focus on the whole person—across all domains of their life and across all systems, programs, and settings through which they receive services. Through integrated care coordination that spans health, medical, dental, long-term care delivered through OPWDD, natural and community resources, and services delivered through other systems, the care coordination team will have better access to the right information at the right time. They will be able to help individuals make informed choices and provide ongoing individual and family support that can better prevent crises from occurring, crises that often lead to placement in more restrictive settings, higher health care costs, and lower satisfaction/quality of life.

Key Components of the People First Waiver Quality Structure

Accountability for Health and Safety

New York will ensure that appropriate and effective systems are in place to meet the core health and safety needs of individuals with developmental disabilities. Agencies will continue to implement systems that provide individual supports and treatment to meet identified needs and ensure regulatory compliance. A robust system of oversight and monitoring will continue to be essential to regularly evaluate the effectiveness of those systems.

OPWDD is making significant reforms in the quality management practices including improving the incident management systems that focus on health and safety and supporting agencies' capacity for quality improvement. This reform agenda and related changes will continue in the People First Waiver. Ensuring the health and safety of the individuals who receive supports and services is the foundation of any expanded focus on quality.

Measuring Quality

Quality will be measured based on outcome indicators related to the identified personal outcomes for each individual receiving services. Agencies will establish systems to address self assessment, correction and quality improvement. Personal outcomes are based on an individual's interests and needs. They are developed through a person-centered discovery process and include the four OPWDD outcome domains of health, work/meaningful activities, relationships and home. Recognizing that the quality of a person's life is directly impacted at the moment when needed support is provided, quality improvement approaches that build the capacity of direct support professionals to deliver supports in a manner that embraces the dignity of each person will be expected from DISCOs and providers.

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Agency outcome measures will indicate the agency's effective provision of responsive services that address individual's personal outcomes including health and safety as well as the provider's systems that support their ability to deliver on personal outcomes. These systems could include an agency's fiscal systems, governance structure, workforce development programs, and quality improvement systems.

OPWDD expects that all agencies will aggressively work to improve quality on all levels and in all areas and seek to improve people's lives in measured ways. The measurement of quality will align with the established mission, vision, values and guiding principles of OPWDD. The indicators identified to measure quality will be meaningful with respect to the person receiving services and be readily available to the providers of service. Quality must be ensured in all interactions with the person.

The Quality Scale

Quality cannot be ensured through regulatory compliance oversight alone and must come from the independent and aggressive actions of the service providing agencies. A rating system called the Quality Scale will set clear expectations for the quality performance of service providing agencies and encourage them to identify and correct problems immediately and to make sure the corrections occur across all services for all people. Establishing a clear statement of the indicators that will be used to measure quality will lead agencies to develop systems and practices that enhance quality of life for those they support. Each agency should ultimately develop a dynamic quality improvement plan which sets aggressive goals as needed for self improvement under the oversight of OPWDD.

The Quality Scale has defined benchmarks which differentiate one level of quality from the next, describing five different levels of quality in an agency's operations. At level 1, the agency requires OPWDD monitoring and is just meeting regulatory requirements. At level 5, the agency has an aggressive action plan for self correction and self improvement and does not depend on OPWDD for traditional regulatory oversight.



Agencies that receive a Quality Rating Level 1 or 2 (indicating low performance) will be closely monitored for their ability to meet the health and safety needs of the people they support. A greater level of technical assistance and oversight will be provided to low performing agencies. Agencies that do not correct their low performing status will not be allowed to continue to deliver services. Agencies that are rated as a Level 5 will be considered for expanded responsibility.

Reports resulting from quality reviews will clearly summarize outcomes and provide meaningful, actionable information to decision makers. The Quality Scale and the ratings of agencies will be available to the public through a variety of means (e.g. web-based publication). They will assist stakeholders such as individuals and families to make informed decisions about which service provider they would like to provide their services and also help them hold providers accountable for the quality of service that they deliver. The Quality Scale will help agencies develop overall strategies for improving their ability to help people live richer lives and the capacity to translate these strategies into operation.

The six domain areas in the Quality Scale are:

1. Individualized Services, Planning, and Service Delivery

The plan of care is developed based on an individual's assessed and desired health and his or her functional and personal outcomes. It is delivered through a comprehensive care coordination approach with the ultimate goal of improving the quality of life for the person receiving supports.

2. Protections/Health and Safety/Rights and Environmental Supports

Individuals receive supports and services in environments that meet or exceed guiding regulations in the areas of health and safety. Incident management systems are well established and serve to identify areas requiring correction, and systemic correction is completed as appropriate.

3. Supporting Family/Natural Supports and Community Connections/Community Inclusion

Opportunities for individuals to maintain and establish relationships should be supported and nurtured. Ideally, individuals should be supported in multiple social roles.

4. Workforce Performance

The workforce is stable and competent to support individuals in a person-centered manner. The workforce is diverse and provides supports that embrace a range of ideas and cultural expression.

5. Quality Improvement Plan

Agencies demonstrate processes that support continual quality improvement. Stakeholders, including individuals who receive services, are represented in aspects of the quality improvement initiatives.

6. Governance and Leadership

Agency leadership is responsible and accountable for the provision of quality, person-centered supports. Leaders ensure that a clear vision and mission focused on improving individuals' lives is both communicated and demonstrated in action.

Quality Scale Ratings**0. Early Alert Agency**

OPWDD is considering or taking adverse action against the agency or one or more of its programs. Individuals served by this agency are considered to be at risk. OPWDD is conducting frequent monitoring visits.

1. Significant Improvement Needed

The agency does not provide adequate services in one or more areas. Stakeholders are dissatisfied with services. Despite technical assistance, the agency has difficulty achieving and/or maintaining minimal regulatory compliance. There are no current immediate danger situations at this agency. The Board of Directors is not providing adequate governance to the agency or guidance to agency management.

2. Inconsistent Provision of Adequate Individualized Services

There are not good systems in place to ensure programs operate effectively. The strength of the program depends on the strength of the individual program manager, and OPWDD has received and sustained complaints from stakeholders against individual programs and services. Site reviews at individual programs have identified some serious deficiencies. Once deficiencies are identified to the agency, the agency does act to correct them for at least the individual program cited. The agency has demonstrated limited ability to self-assess its operations. The agency is fiscally viable. The agency has an active Board of Directors that responds to issues identified by external regulatory agencies, but does not have strong governance practices that would identify and prevent serious issues from occurring.

3. General Compliance with Regulations-Beginning to Work on Quality Management Plan

All programs and services meet regulatory requirements for the provision of health and safety services, but all or some could improve in some quality areas. The agency uses some person-centered planning principles, but has not fully developed practices that ensure its use on a consistent and integral basis. The agency takes responsibility for correcting deficiencies identified by state regulatory agencies and addressing complaints from individuals, but should improve systems to self identify issues that need correction. There is evidence of an active Board of Directors that provides fiscal and policy direction to the agency management and responds to issues identified by external review agencies and agency management. The agency is fiscally viable.

4. Self Survey and Quality Improvement Plan Implemented and being Evaluated (An Emerging Agency)

The agency has consistently provided services that meet the health and safety needs of individuals. Services, in general, are individualized and person-centered. OPWDD has received minimal complaints that have been sustained from stakeholders regarding the quality of services they are receiving. There is evidence of an informed and involved Board of Directors that is independent from, and provides sufficient guidance to, agency management. The agency engages in self-assessment

activities and is responsive to requests from OPWDD and other agencies to serve individuals in crisis or individuals who have been misplaced or have challenging needs.

5. Fully Implemented Quality Management Plan with the Highest Standards of Service in OPWDD

The agency consistently provides high quality, individualized services. Individuals capable of proactively expressing their opinions are strongly involved in choosing and planning their services; for those individuals unable to proactively express their opinion due to profound intellectual and multiple disabilities, the agency has adopted or created meaningful methods to intuit the preferences of these individuals that include observation and interaction with the person and do not rely solely on projecting the choices and opinions of others onto the individual. The agency implements an effective self-assessment system that results in continuous improvement in the quality of services and the satisfaction of individuals being served. There is evidence of a fully informed and involved Board of Directors that is independent from and provides sufficient guidance to agency management. The agency initiates plans to serve individuals in crisis or individuals who have been misplaced or have challenging needs. Through connections at the local level, the provider seeks opportunities to change misperceptions about individuals with developmental disabilities through natural relationship building and modeling of respectful interactions.

Quality Measures for DISCO Operations

Quality measures for the DISCO will be established separately from the Quality Scale. Measures for the DISCO may include but are not limited to: care coordination measures, responsiveness to advocacy, fiscal viability, resource allocation, and operations, DISCO governance, corporate compliance measures and the effective separation of duties (i.e. provider vs. MCO role); delivery of informed choice; diversity of provider networks that can deliver culturally competent services.

Getting From Here to There Over the Next Five Years

The People First Waiver is New York State's opportunity to broaden the supports and services available to individuals with developmental disabilities through a more flexible and person-centered approach to service delivery while bending the cost curve for sustainability of the system for years to come. The use of a consistent assessment process that drives life planning and equitable resource allocation and the strengthening of the care coordination process are critical pieces of the waiver. In line with these changes, quality must be measured based upon the outcomes of the person receiving services. If the person's health and functional and personal outcomes are met in a way that enhances his or her quality of life, then quality has been achieved. The concepts and the rating system, as defined in the Quality Scale, are meant to drive quality improvement within agencies to ensure that their practices and actions focus on achieving quality outcomes for the people they support.

Although there is much work yet to be done, we fully expect that on “day one” of the People First Waiver, all services and supports currently delivered to people in our system will transition smoothly into the People First Waiver. OPWDD will continue to meet the same needs for service. However, the new waiver will allow us to review how well the current options are supporting people and what ways we could do things better and promote better personal outcomes for individuals and families.

Over the five-year course of the waiver, OPWDD will implement and evaluate pilot projects that carefully test ways to improve access to services, develop new service options, organize care, pay for services, and measure quality. The ideas that work well will ultimately be made available on a statewide basis, with careful and thoughtful implementation and continuous dialogue with the people we serve. The transition, from testing of ideas to statewide implementation, will take place over an extended period of time with extensive communication and carefully structured transition plans. The services people receive may change somewhat, but the changes will always be done carefully and in a transparent way with advanced notice to individuals and families.

*OPWDD envisions three
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- 1. Implementation
Planning*
- 2. Pilot Projects and
Testing of DISCO
Operations*
- 3. Roll Out of Successful
Models*

Initial Building Blocks for an 1115 Waiver Implementation Plan

OPWDD envisions three broad phases of waiver development:

1. Implementation Planning
2. Pilot Projects and Testing of DISCO Operations
3. Roll Out Successful Models

Phase 1: Implementation Planning and Evaluation (October 2011–Spring/Summer 2012)

- OPWDD staff will process and incorporate the input provided through the 5.07 Public Hearings into the final People First Waiver reform recommendations.
- OPWDD will work with CMS to initiate a revised institutional rate for its developmental centers (campus-based ICF-DD programs).
- OPWDD will continue to communicate regularly with our stakeholders and CMS regarding plans for the waiver through formal presentations, informal discussions, the People First Waiver Web page, the listserv and other communication mechanisms.
- OPWDD will develop initial interim work plans and functional and administrative alignment for the operation of pilot and demonstration projects while continuing to sustain existing service system.



- OPWDD, together with stakeholders, will develop an interim plan for ensuring short-term fiscal sustainability while we build the new system of reforms that will ensure the long-term sustainability of the system. This work will be ongoing over the next several years and will focus on such things as:
 - Streamlining administrative requirements, procedures and paperwork wherever possible which support greater emphasis on service delivery and personal outcomes
 - Encouraging, supporting, and facilitating shared “back office” functions and/or consolidations among providers
 - Paving the way for cross-systems collaborations that will lead to more integrated options for individuals served. For example:
 - Work with the Department of Labor to review regulations and obstacles to shared living and live-in-caregiver approaches that have prohibited more innovative residential support options;
 - Undertake a comprehensive review of cross-systems regulations and laws that may prevent behavioral supports from being delivered in non-certified settings;
 - Reexamine the Nurse Practice Act as it pertains to people residing and working in community integrated, non-certified settings;
 - Examine barriers to medication administration in non-certified settings;
 - Identify barriers to using technology supports to provide safety and oversight; and
 - Examine and address ambiguity and overlap between OPWDD and ACCES-VR and key aspects of special education.
 - Streamlining and simplifying self-directed service options and further developing capacity to deliver seamless employment supports and residential supports for people living in non-certified settings
 - Working with stakeholders to establish prioritizing guidelines that will speed access to services for everyone, while ensuring that individuals and families with the greatest need for comprehensive services receive needed support
 - Developing sustainable policies for new supports and services for new individuals entering the service system
 - Developing transition plans for the phase-out of fee-for-service structures and
 - Determining how existing and potentially new property costs will be transitioned to and managed within the new structure.
- OPWDD will revise the state-operated rate methodologies to align payments more closely with the cost of providing services in these settings.
- OPWDD will continue to work on transition plans for moving individuals residing in state-operated institutional settings into community integrated settings with appropriate levels of support for them to be successful.

Phase 2: Pilot Projects and Testing of DISCO Operations

- Test the DISCO operations through pilot projects that identify the essential elements that will be common across all DISCOs (although based on local needs and resources, some of the ways DISCOs are organized may differ).
- Develop contract mechanism for DISCOs and contract criteria for providers that will contract with DISCOs.
- Transition from the current fee-for-service system to a capitated payment methodology, including identifying how existing and potentially new property costs will be transitioned and managed.
- Develop and/or revise regulations and guidelines for DISCO operations.
- Develop the DISCO's reporting structure.
- Develop Needs Assessment instruments that will drive more equitable resource allocation and inform the ongoing person-centered care planning process.

This is a foundational component of the 1115 waiver reforms. Through the use of a consistent measureable process, clearer determinations of resource allocation can be established and greater equity of resource distribution can be realized. It is anticipated that the equitable resource process will incentivize providers to develop more innovative supports that better align with individuals' interests and needs.

- Realign and/or redesign the role, responsibilities, and functions of Developmental Disability Services Offices (DDSO) and OPWDD Central Office Divisions/Units to effectively support the operations of the People First Waiver infrastructure.
- Streamline developmental disability eligibility processes through No Wrong Door (the ability to access the appropriate supports and services no matter which agency or organization you arrive at first).
- Overhaul regulations and policies that do not align with the new waiver (e.g., OPWDD HCBS regulations) and incorporate regulations and policies that are necessary for safeguards and oversight of the new system (e.g., due process and grievance mechanisms to resolve differences between individuals and the DISCO/service providers).
- Develop, redesign, and integrate robust and comprehensive information technologies.

Ensuring Choice

Throughout each phase of the waiver individuals with developmental disabilities will have choice between plans, and within these plans, individuals will also have a choice of providers and ample opportunities for self-direction including both individual employer and budget authority.

New York will take steps to ensure there is an appropriate diversity of providers, in line with individuals' interest in aligning their cultural, community and family histories with a provider of their choice.



Phase 3: Roll Out Successful Models

Developing Services and Supports and the Service Delivery Infrastructure

It is New York's intent to use the entire five-year period of the People First Waiver to develop the programmatic expertise and provider capacity needed to initiate care coordination that incorporates the full spectrum of medical and developmental disability specialized services into a single, integrated comprehensive service delivery system which integrates Medicare and Medicaid financing.

- Transition the system to integrated care coordination provided or contracted through the DISCO. This transition will begin the statewide expansion of those methodologies demonstrated by the pilot projects to be the most successful at supporting personal outcomes for individuals while better integrating services and enhancing care coordination:
 - Develop a system to require real person-centered planning and related integrated care strategies.
 - Design and define care coordination role, functions, and benchmarks.
 - Develop the tools and strategies for ongoing assessment and the systems and mechanisms for comprehensive care planning across systems.
 - Build capacity for comprehensive care planning in all life domains in an integrated way including health and medical care.
- Revise service delivery infrastructure (e.g., policies, administrative memoranda, regulations, guidelines, etc.) to support DISCO operations and new service categories (i.e., individual and family support; community integration and habilitation; flexible goods and services; home and community-based clinical and behavioral supports).
 - Design a system for providing independent advocacy.
 - Redesign self-directed service options to ensure simplicity and a continuum of options, from choosing your own support staff to full budget authority (choice and control of an individual and self-directed budget).
 - Design criteria for flexible goods and services.
 - Tailor residential support options to the new waiver framework.
 - Examine opportunities for efficiently funding real property/capital infrastructure.
- Build statewide capacity to deliver individually tailored clinical, behavioral, and crisis supports for people leaving state-operated institutional settings and for people to reside in the least restrictive settings possible. Components include but are not limited to:
 - Clinical coordination to ensure that individuals are provided with the needed supports outside of the highly structured state-operated institutional setting. The coordination of behavioral health supports is critical to maintaining and ensuring clinical stability.
 - Community-based group and individual counseling – Many individuals transitioning from state-operated institutional settings, and those served in community settings rather than an institutional setting, need counseling to help with relapse prevention, anger management and development of coping strategies.
 - Effective community crisis supports are needed to transition individuals out of state-operated institutional settings and to avoid the reliance on institutional models of support for people in

community settings who present with behavioral crises. Needs for crisis supports exist across a variety of settings, including family homes, independent living settings, and in certified settings.

- The development of effective behavioral supports requires changes in practices to broaden the support available to people in non-certified settings. Clinical supports must also be more broadly available to people across all settings, including those that are non-certified. Consistent training to services providers and families is required.
 - Person-centered planning should drive the appropriate residential supports for people who are transitioning out of state-operated institutional settings and for people who are at risk of or have been referred to state-operated institutional settings historically. Determinations should be made about the appropriate residential support model based on the individuals' expressed interest and their identified risk.
- Align roles, responsibilities, functions, provider qualifications and workforce competencies and training expectations with DISCO operations and the new service delivery infrastructure.

Enhancing and Aligning the Quality Infrastructure

- Develop OPWDD's new quality management strategy and infrastructure for the People First Waiver that will focus on the following:
 - Building a culture of respect for the individuals and families receiving supports and services;
 - Ensuring appropriate, person-centered support models that protect the health and safety of individuals, employ a consistent needs assessment process, and identify personal outcome measures; and
 - Carefully evaluating personal outcomes for individuals through systematic reviews and processes that effectively identify both best practices and areas requiring improvement.
- Operationalize the Quality Scale across all OPWDD oversight functions, and in particular, in the operations of the Division of Quality Management and the DDSOs.
- Develop and implement quality review for DISCOs including standards for governance, fiscal viability, and other related quality criteria.

Formal Evaluation of the People First 1115 Waiver

- Develop and implement the infrastructure for the required formal evaluation of the People First Waiver as required by CMS.



Conclusion

The People First 1115 Waiver is the vehicle that will carry New York State's developmental disabilities service system to the next level of system performance with improved care coordination and flexible delivery of more personalized services, greater efficiency and accountability. Achieving this system advancement will build on the rich history of state and stakeholder partnership that has transitioned New York's system of support for individuals with developmental disabilities from an institutionally based system to one now soundly based on community-based services.

The People First Waiver is the mechanism through which this same partnership has articulated and can now achieve a shared vision for yet more responsive services delivered to more people in the least restrictive environment. Redesigning the administrative and fiscal platforms that support the delivery of services represents a significant turning point, a necessary paradigm shift that will continue the evolution of our service system. Making it truly express a collective vision will require the energy, creativity, passion, expertise –and commitment – of many parties.

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Working together, we must continue to communicate, listen, and plan creative and constructive reforms to make sure the changes work for the people who rely on the system to attain the lives they desire and deserve. This report is only the beginning, the starting conversation that launches a very large construction project. Next, we begin the process of piecing together the building blocks –the pilot projects and implementation planning –that will help us develop a real, workable blue print for building a reality to match the vision.

Appendix A: Summary of the Listening Sessions



Report of the People First Waiver Listening Sessions

June 2011



Courtney Burke
Commissioner



Andrew M. Cuomo
Governor



Nirav R. Shah, M.D.
Commissioner

The People First Waiver

The New York State Office for People With Developmental Disabilities (OPWDD) and the New York State Department of Health (DOH) are developing an application to the federal Centers for Medicare & Medicaid Services (CMS) for a new 1115 research and demonstration waiver to develop and test significant programmatic and fiscal improvements to the developmental disabilities service system. This waiver, known as the People First Waiver, will provide a timely opportunity for New York to further advance principles of quality, choice, and community as the core elements of service delivery while modernizing fiscal and administrative operations to ensure sustainability for years to come.

Gathering Initial Impressions

The process of redesigning the service system to deliver high quality, personalized care in more responsive, efficient, and accountable ways is a significant undertaking that requires the ideas and input of many parties. Over several months, OPWDD will work with individuals with developmental disabilities, family members, service providers, key State agency leaders and staff, and outside experts in health care and long-term care to design critical elements of the new service system needed to deliver the stated goals of the People First Waiver. This process began in April 2011, when OPWDD Commissioner Courtney Burke traveled around the state to meet with individuals with developmental disabilities and family members. These “listening sessions” occurred at seven locations across New York State, and more than 270 people took time out of their day to share their thoughts with Commissioner Burke. During these sessions Commissioner Burke invited comments around four questions and listened as people told her of their experiences in the service system and their desires for the future. The questions that shaped these conversations were:

1. What is working well for you?
2. If you could change one thing about the way OPWDD supports you, what would it be?
3. How can OPWDD empower people to lead a fulfilling life?
4. How can we best determine individuals’ needs and allow that understanding to drive the “right” level of support for that person?

This report summarizes the comments heard during these listening sessions and will be used to shape the final design of the People First Waiver and the future service system.

Question #1

What is working well for you?

Family Support Services

There was broad consensus that Family Support Services (FSS) remain essential to helping families of individuals with developmental disabilities enjoy a positive, rewarding life. From making recreation programs available to a child with a disability to providing respite from the demands of caring for their loved one, supporting families where and how they need support is one of the most valued services OPWDD offers. Family members told us:

"FSS is essential to provide kids with recreation programs. The recreation programs lead to friends."

"FSS works well. My sixteen-year-old lives at home. He goes out into the community and we can give time to his siblings."

"FSS has been wonderful. The sibling workshops have been priceless."

Parents told us that families need support managing the needs created by their child's disability and that often, just a little help can make a huge difference. They said that keeping their children in their homes improved everyone's life, and that FSS needed to remain flexible to provide different kinds of supports for different family situations. They also repeatedly requested support for connecting to other families of children with developmental disabilities. Families do the best job supporting their loved one, we were told, and family-to-family connections can be a critical lifeline, enabling families to help each other.

Consolidated Supports and Services (CSS)

Across the state, it was clear that CSS is allowing a level of independence and control that has improved the quality of life for many individuals. Many attested to the benefits of being able to hire their own staff and pay them appropriately and told of living more inclusive lives with greater choice and opportunity. Two parents offered these specific comments:

"My daughter has been in CSS since she was six. I have seen enormous growth in her. It is great not to have to deal with all the agency rules and regulations. It is about her, and it is working."

"My 32-year-old son received no services before age 25. He now has CSS and has choice and meaningful relationships."

But, we also learned that CSS, for all its benefits, can be difficult to implement. Some parents and individuals reported the need to make it more widely available and allow people to hire members of their families as their support staff. They asked that CSS offer greater flexibility to accommodate changes in people's service needs and to work in combination with other services.

Residential and Day Services

In every region of the state, families reported the positive impact of residential services and day services on the lives of their loved ones. People described how their children were experiencing life in the community, meaningful activities, and employment. We heard:

"Community habilitation services have helped maintain a normal life for the entire family."

"Residential services, day habilitation, and supported employment are working well for my son. He now has a life in the community. Before, he was in an institution."

"My daughter loves her sheltered workshop. It works well for her because she has great difficulty being in the community."

At the same time, we learned that growing waiting lists for residential services are a major concern for many, that parents whose children are still in school fear the unavailability of residential services when their children reach adulthood, that day habilitation programs are sometimes not available, and when they are, their services are not always individualized to meet each person's unique learning needs. We were told that expectations around work are too low, that employment should be the first option for all those who want to work, that working even a few hours each week can dramatically change someone's self image and their life, and that more pre-vocational services are needed to prepare people for work.

Medicaid Service Coordination (MSC)

Commissioner Burke also heard many comments about MSC and the central role it plays in keeping people connected to their communities and the services they need. She learned that a service coordinator is often a consistent, trusted advocate who people come to rely upon for stability, especially as life brings its inevitable twists and turns, and needs change. Many people also voiced concerns over recent changes in the MSC program and how diminished MSC visits might impact the lives of individuals. Some called for better information for MSCs, better pay, and MSC training that is consistent among agencies and available to family members as well as service coordinators.

Question #2

If you could change one thing about the way OPWDD supports you, what would it be?

Commissioner Burke heard many answers to this question, specifically, answers related to improvements to specific service types or service coordination to increased funding and system oversight and quality.

Services

Comments related to services frequently expressed concerns for continued funding and availability of services. These comments were most often pertinent to Family Support Services, residential services, as well as day habilitation, pre-vocational and supported employment services. Beyond these fears, however, OPWDD received many thoughtful comments about particular aspects of its service system that families and individuals have found need improvement. Their experience indicates the following:

Family Supports

- Families need to connect to each other. One of the most important things OPWDD could do to support families of individuals with developmental disabilities would be to help this happen.
- Families and individuals need assistance in managing behaviors. Family members of individuals who live at home, staff in group homes, and respite workers need appropriate training related to managing and intervening in challenging behaviors so that individuals can live at home, attend respite and be better served in residential settings.
- Families need crisis services that will provide a place for a loved one in crisis so that individuals have an appropriate place to go rather than the emergency room or local psychiatric hospital, where their needs are not understood.

Residential Services

- Some parents described how their children had to be served in other states and other communities and expressed their desire to access services in their own geographic areas.
- Residential services need to offer a wider range of support, providing lower levels of staffing at less restrictive settings and moving away from “cookie cutter” services that can be overly restrictive for some residents.
- Concerns for safety often trump quality of life considerations, leaving people safely idle and unengaged in the community or any meaningful activity. Resulting boredom, in some instances, has lead to increased behavioral challenges such as self injury and a need for increased medication.

Service Planning & Coordination

- While those who receive person-centered planning enjoy services designed around their unique needs and ambitions, many people in the service system still do not receive this level of individualized service planning. All individuals require access to person-centered planning.
- Transitioning from school systems to adult services remains a difficult time for individuals and families as many who have been served solely by school districts prepare to enter the OPWDD service system for the first time. Assessing individuals' needs for adult services and preparing them and their families for navigating the OPWDD and ACCES-VR (vocational rehabilitation service system) requires improved support from school districts that are knowledgeable about adult services.
- Medicaid Service Coordinators need to make a person's goals relevant. Having positive relationships in life may be more important than someone developing a particular skill.

Equity of Access to Services

- People who are medically involved often experience limited options for community inclusion. For them, finding a way to support engagement in the community is an important system change that is needed.
- People with the fewest needs are easier to serve and sometimes receive services when those with the greatest needs are not.
- In addition, many people expressed their desire for more equitable access to services across the state, noting that where one lives should not dictate the services available. Presently, people residing in the rural areas of the state have more limited service opportunities, and more individualized options like CSS are not available equally across the state.

Quality and the Workforce

Many parents and individuals commented about the importance of the direct support workforce in the quality of the service system. Training staff to respect individuals and understand and meet their needs is foundational to a quality system. In addition, they told us that OPWDD needed to check the background of direct support staff, and the call for improved pay that would more appropriately reflect the value of direct support work was heard in every session. Many called for improved accountability and oversight of the workforce and better protections for people who are unable to protect themselves. Some specific comments included:

"Staff need to be trained in person-centered supports before they work with individuals."

"Staff need training in abuse prevention."

"OPWDD needs a special victims unit to help the special needs victims. Agencies need training in how to assist the victim"

"I fear the budget cuts will mean changes in staff for people who need consistency."

"We must value the direct support professionals more. They are the moms and dads for the people they serve."

"A comprehensive approach to quality is needed rather than one solely focused on incident reporting."

"Too much reporting takes time away from the people being served."

Fiscal Support

Many people expressed grave concern for the future fiscal support of the service system. These comments focused primarily on two concerns: the impact of budget cuts on future services and the desire to see funding used more directly to support people. Many people voiced concern that day and residential services would not be available for their children when they leave high school or are ready to move out of the family home. Others said they wanted to know where the funds come from that support their child's services and how they are used by provider agencies for those services. And still others said people receiving services should be able to take the funds that pay for their services to different service providing agencies of their choice.

In addition, parents noted that some of the more individualized and empowering services (CSS, supported employment) are supported by lower reimbursement rates and therefore are less attractive to service providers.

Finally, families told us the reliance on Medicaid funding for all services has meant the system is less flexible and more limited by rules regarding what services can be provided and how they can be delivered. In some instances, parents described how Medicaid rules meant services were no longer as responsive to individual needs as they once were.

"Using Medicaid has meant billing only for one service per day so that my daughter needs to take another day for a second type of therapy and cannot go to work another day. This means she has to stay home in a residence where she is the only verbal person. This has caused depression and a need for medication."

Question #3

How can OPWDD empower people to lead a fulfilling life?

Individuals and family members had many good ideas for how New York State can better empower people with developmental disabilities to live rich and fulfilling lives. Increasing the role of family members and individuals within the service system clearly topped the list. Commissioner Burke heard comments such as:

"Give parents more than a token role in decisions."

"All trainings should have self advocates and individuals with developmental disabilities present."

"You need to really listen to the people who receive services."

"Listen to families and engage them. They know what is needed."

Beyond providing a louder voice for individuals and families, she heard calls for the following empowering measures:

- Increase flexibility and choice.

"Siblings at home are the best persons to work with individuals. People need the freedom to hire whoever they want to hire. A brother working with a sibling can be the light of that person's life."

"It boils down to providing opportunities for choice – whether it is a workshop a day hab, or a volunteer opportunity in the community."

- Maximize the talents and capabilities of those we serve.

"Helping people to do whatever they can do will empower them."

- Training – Give people opportunities to prepare for community living, to learn important basic skills such as cooking, banking, shopping

"The more you can do, the more confident you are."

- Increase opportunities for self direction, with easier access to self direction.

"Make CSS less overwhelming. Streamline the process."

- Provide advocacy and assistance and training in navigating the system.

“Keep educating people about service options and providing choices.”

“We need someone from the State to be an advocate – to help families navigate the system.”

“Many families don’t know who to talk to or how to get information. It takes a lot of work to find things out.”

“Helping people network is essential to empowering them.”

“All DDSOs need to have parent groups. It helps a lot.”

- Provide personalized services and more meaningful community activities.
- Empower direct care staff with better training and pay.

“Staff are everything to families.”

- Increase opportunities for employment with equal pay.
- Keep OPWDD a distinct agency.
- Establish centers of excellence in service delivery and facilitate replication.
- Promote acceptance of the differences in all people.

“Peers must learn from a young age that there are differences in all of us.”

Question #4

How can we best determine individuals’ needs and allow that understanding to drive the “right” level of support for that person?

As OPWDD makes its services more personalized and uniquely responsive to each individual’s unique needs, the manner of assessing someone’s needs becomes critical in providing appropriate care. At the listening sessions, self advocates and family members reiterated their own key role in identifying a person’s needs and then went to make the following comments and suggestions:

- Disability Determination Packages (DDPs) are deficit-based. Instead, we should focus evaluations on what a person can do. Make assessments asset-based.
- Communicate with the education system so that OPWDD services are based on all the knowledge of a person's abilities and can be prepared for the "tsunami" of need that lies ahead.
- Recognize that you can determine someone's desires even if he or she is nonverbal. Observe their preferences, their likes and interests, and build on those.
- A support intensity scale would allow for a wider scale of supports.
- Diagnoses or lack of diagnosis currently determines the services received.
- DDPs are not accurate. An accurate assessment of need could liberate some people from restrictive settings.
- There needs to be a way to reassess older people using new tools.

Next Steps

Allowing the expressed needs and recommendations of those we serve to continuously inform and direct the process of designing the improved service system is imperative. Over the course of the summer months, the People First Waiver will take shape as the waiver Steering Committee and various design teams explore key areas of service design and delivery, funding, and system administration. Each member of the People First Waiver Steering Committee and each design team leader will receive copies of this listening session report so that this "pulse" of those who receive OPWDD services will guide their work. As the teams begin exploring their distinct areas of concern, OPWDD will provide additional opportunities for individuals, family members, and other interested parties to submit comments, suggestions, and ideas for improving the service system under the People First Waiver. Each opportunity will be promoted on the [People First Waiver Web page](http://www.opwdd.ny.gov/2011_waiver) (www.opwdd.ny.gov/2011_waiver) and directly provide the design teams with up-to-date input from those we serve. The feedback collected through these measures will be summarized and made available for the public on this site, as well.

Commissioner Burke extends her sincere thanks to all who participated in the listening sessions. Their honest assessment of the services OPWDD currently provides supported a critical first step in developing the People First Waiver and has helped to clarify the work ahead. It will serve as a valuable point of reference as the People First Waiver Steering Committee and design teams craft a system that responds to what we've learned.

Appendix B: Summary of the Public Forums



Public Forums Stakeholder Comment Analysis

August 2011

New York State Office for People With Developmental Disabilities
Division of Policy and Enterprise Solutions
Bureau of Planning and Research

Analysis Conducted by: Neil A. Mitchell



Courtney Burke
Commissioner



Andrew M. Cuomo
Governor



Nirav R. Shah, M.D.
Commissioner

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Executive Summary

In May and June 2011, the New York State Office for People With Developmental Disabilities (OPWDD) held public forums and hosted an online survey to solicit public input on the design of the People First Waiver. A total of 251 submissions of written and spoken testimony and online survey responses were obtained. These comments confirm that developmental disabilities stakeholders represent a diverse group of individuals and families with a wide range of service needs and desires. They also demonstrated that, despite their differences, stakeholders agree on many issues of concern and needed service system improvements.

The comments collected contained 1,999 separate comments which fell into five general categories including Supports and Services, Access and Funding, Quality, Community Inclusion, and Individual Control and Personal Development. Nearly half of all comments (975) related to Supports and Services.

Supports and Services

- The two subcategories within this category that received the most comments related to supports for community living, followed closely by comments related to serving exceptional populations, in particular, children, people with complex medical needs, and people with autism spectrum disorders or challenging behavior.
- The most frequently cited need was for respite services.
- People also noted that transportation services, opportunities for recreation and social interaction and community and residential habilitation are extremely important.
- Concerns about staffing, home, employment and day services, and family supports each generated fewer, but still a substantial number of comments, including:
 - Calls for greater availability of residential opportunities.
 - Praise for the work of direct support professionals, calls for improved wages and career potential for these important workers.
 - Calls for greater access to supported employment opportunities, training to prepare for employment and competitive employment and innovative day activities.
 - Calls for new family support services and expansion of existing kinds of supports.

Access and Funding

- The largest number of comments in this category were related to accessing services, followed next by administrative processes, funding, and service coordination. They noted that:
 - Accessing services is a complicated and extensive process and a simpler process is needed.
 - Services and eligibility should be maintained for people currently receiving services.
 - OPWDD should reduce paperwork and streamline administrative processes.
 - Service coordination is vital to families, and service coordinators must be well trained and knowledgeable.
 - Individuals and families want more control over the funds that are allocated to their services.
 - The use of resources should be reviewed to find savings for reinvesting in additional services.

Quality

- Well over half the 217 comments related to quality concerned the gathering of feedback from individuals and families, measuring performance and/or improving outcomes for individuals and the quality of services in general. They noted that:
 - OPWDD should gauge the effectiveness of the service system by surveying individuals and families on what they need and whether or not their services have met those needs.
 - OPWDD should use performance measurements to ensure quality.
 - Individuals and families should help determine how the quality of their services is measured.
 - Oversight and quality assurance are critical to generating confidence in the system.
 - Ensuring safety is critical.

Community Inclusion and Public Acceptance

- Of the 214 comments that were related to this topic, 92 concerned community services and integration.
- Respondents emphasized that the community is the right place for individuals with developmental disabilities.
- The second most frequently cited comments related to OPWDD's communications and public relations. They told us that:
 - For an individual to succeed in the community, he or she must have appropriate support for integration and a community that understands and welcomes them.
 - OPWDD should work with public schools to offer sensitivity awareness training and provide public service announcements to convey how valuable individuals with developmental disabilities are to their communities.

Individual Control and Development

- The 150 comments received in this category were almost evenly split between those that related to individual and family control and those that spoke to how OPWDD services can support an individual's personal growth.
- Respondents noted that they want to be part of deciding who delivers services, as well as where, how and when services are delivered.
- They also noted they want greater flexibility to adapt these aspects of their services as circumstances in their lives change.
- Respondents noted that relationships and friendships are the key to personal growth and a meaningful life. Opportunities to socialize and develop these bonds are important.

The feedback provided at the People First Waiver public forums pertained to nearly every aspect of the service system imaginable. Each person approaches the system with different concerns and at a different point in their lives. Yet each requires individualized support delivered in a caring way by professionals specializing in the diverse field of developmental disabilities. Achieving this outcome is the task of the People First Waiver.

Introduction

In April 2011, The New York State Office for People With Developmental Disabilities (OPWDD) and the New York State Department of Health (DOH) released a concept paper outlining plans for development of the People First (1115) Waiver. Soon after, OPWDD announced a series of People First public forums that would occur in late May and early June 2011 to gather stakeholder input that would shape the system reforms within the new waiver. Sessions were held across the State and via webcast to provide ample opportunity for interested parties to contribute comments.

Family members and individuals, agency staff and executives, advocates for people with developmental disabilities, and other stakeholders presented their viewpoints at the forums. In addition, an online survey was conducted, an email address was created to accept submissions of testimony, and written testimony was accepted by mail. A total of 251 submissions of written and spoken testimony and online surveys were received. Respondents were asked to focus on four questions:

- How can we further break down barriers and support people to live truly integrated lives in the community?
- What do families need to better support their loved ones at home?
- What reform ideas do you have to help us operate more efficiently so that more funds can be directed to the services and supports people need to be healthy and engaged in meaningful work and activities?
- What should we be measuring to tell us if we are doing a good job supporting people to have good health, positive relationships, live in homes of their choice, and enjoy meaningful activities and employment?

Participants often responded to these questions directly, or presented on a topic particularly important to them. General themes from the responses emerged, and these themes and the wishes of those who offered feedback are analyzed in this report. In the next section, some of the responses received to the four questions from our stakeholders are shared.

Selected Answers to the Four Questions

Speakers at the public forums and respondents to the online survey and mailbox were asked to consider four questions. The answers to those questions that are described here represent the general comments received, but do not capture all the viewpoints that were expressed. Below are some of what respondents had to say. (Note: some quotations have been paraphrased without altering their meaning.)

Question 1: How can we further break down barriers and support people to live truly integrated lives in the community?

"Breaking down barriers as well as providing support for individuals requires education of the community but also requires compassion and consideration for every individual."

"Community integration relies on direct support workers being trained and strong."

"Enable people with disabilities to live in their own homes and receive individualized supports on an as-needed basis."

"Offer more community habilitation training to instruct appropriate behavior in community settings and foster community acceptance."

"The general public needs to know that people with a disability have the same dreams as the non-disabled."

"Promote partnerships with community employers; employment and volunteerism enhance community integration and acceptance."

"Assist families in creating communities and programs without walls to support their children in developing full and rich lives that are integrated into the mainstream."

"Provide a means of transportation for those who may need it."

"Consolidated Supports and Services (CSS) has been truly successful for my daughter in this regard. We look at her neighborhood as having possibilities for her to be of help to her neighbors."

"Instead of having agencies only offer programs to people who receive waiver services, programs need to include community peers of the same age, or even siblings."

"The service plan should have meaningful outreach and education in each community."

"I believe that schools need to provide more education to the students to make them aware of what having a disability is about."

Question 2: What do families need to better support their loved ones at home?

"We must provide meaningful and individualized services in the family home, and that will require enhanced staffing for some. This will allow families to take a break and extend their willingness to keep their children home."

"Respite would be at the top of my list. Our family has out-of-home respite which is so useful to us."

"Funding to be able to put special equipment into the home."

"Afterschool care is critical to our family, as it is the only way that we are able to maintain our jobs, cover doctor and dentist appointments for ourselves and sons, attend school functions, or just shop for groceries."

"Families must be educated and trained in the specialized care that their loved ones need. If families have a better foundation and understanding of these needs, then they would be more likely to know how to care for their loved one."

"For basic safety reasons, parents/caregivers and at-home service providers need to be trained in crisis intervention techniques."

"Families need to have the opportunity to have input into the design and re-design of OPWDD changes."

"Individuals need adequate daytime services in the community with adequate transportation to get there."

"If a family has a relationship with a provider (or service system in general) who they believe could step in if they needed them (and how they need them) then they will be more likely to keep a family member at home for as long as possible."

"Families need support services that are easy to access."

"We need support groups and more availability of service coordinators."

"Individuals and their families need to be made aware of available services/options and learn how to access services. We need to improve familiarity via education, advertising, and outreach."

"Families need to have a plan in place so that their loved ones are cared for when they are unable to do so."

Question 3: What reform ideas do you have to help us operate more efficiently so that more funds can be directed to the services and supports people need to be healthy and engaged in meaningful work and activities?

"Making services more personalized is key. Every individual served has different needs, and to be offering the same 'boxed set' of services is no longer feasible."

"Self-direction is fiscally responsible and should be available to everyone."

"Cut down on the amount of paperwork."

"Support transparency. If we have a better understanding of where funds are spent, we can choose or at least have a say in how they are spent."

"The regulations need to get carved down to a manageable level."

"Generic community resources can be accessed to meet the needs of the person. The person is now more a part of the community and it is less costly to OPWDD in the long run."

"Efficiencies need to be reinvested to address other areas of need (like wait list pressures and staff retention and salaries)."

"Ensure that agencies providing similar services to similar individuals in need are being reimbursed at the same rates."

"Every situation has to be looked at. Are the right people being put into group homes? Are they getting the level of support they need in the home? Is it too much support or not enough?"

"Encourage and support provider agencies to reinvest funding into needed services."

"I would like to see a model moving in the direction of measureable outcomes."

"Allow easier access to OPWDD and OMH services at once since there are so many individuals who are dually diagnosed."

Question 4: What should we be measuring to tell us if we are doing a good job supporting people to have good health, positive relationships, live in homes of their choice, and enjoy meaningful activities and employment?

"Surveys of OPWDD's services need to be conducted regularly, goals and benchmarks established, and programmatic changes made to reflect the needs of an ever-growing, ever-changing population."

"Quality indicators for housing options include choice, safety, adaptive equipment and a home representative of the community in size and appearance."

"Send yearly surveys to individuals and/or family members to rate their satisfaction with services."

"Quality must be expressed in tangible terms, and then measured through an integrated and comprehensive quality assurance/improvement program. All stakeholders in an agency can establish the definition of quality."

"Meaningful statistics like the number of people living on their own or with others of their choosing where they want in the community, the number of relationships with nonpaid supports, the types of activities and hours spent in meaningful activities like volunteering or working a job, going to school, etc."

"Before measuring good health, etc., there would need to be a way to define what that means for an individual. Good health for one person may be reducing the number of visits to the doctor for infections, or it could mean maintaining a certain blood pressure for another."

"Statistics – measure goals and outcomes."

"Ask the people we support! Using qualitative measures for assessment can improve quality of life for the people we support."

"Indicators mean vastly different things to a person who is moderately disabled and one who is profoundly disabled. Do not apply the same standards to each."

"Conduct a baseline survey, with follow-up each year, to determine progress and ask for examples of best practices that can be shared with the rest of the State."

"Develop a questionnaire for the individual or families before and after the service is implemented."

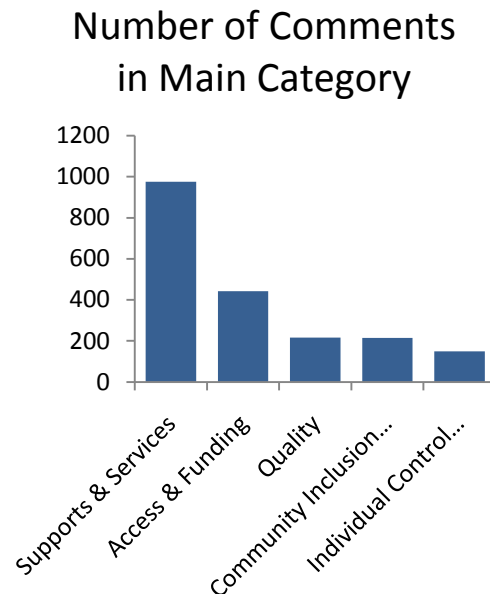
Main Categories of Comments

There were 251 responses from public stakeholders regarding the development of the People First Waiver. From these, a total of 1,999 separate comments were identified and categorized.

In broadest terms, these nearly 2,000 comments can be categorized under five main categories:

- Supports and Services (975 comments, 48.8%)
- Access and Funding (443 comments, 22.2%)
- Quality (217 comments, 10.9%)
- Community Inclusion and Public Acceptance (214 comments, 10.7%)
- Individual Control and Personal Development (150 comments, 7.5%)

Nearly half of the comments related to *Supports and Services*, and this includes individualized supports, family supports, housing and other services. *Access and Funding* comments related primarily to streamlining procedures, funding and billing, and breaking down administrative “silos” to provide better coordination of more comprehensive care. Comments regarding *Quality* related broadly to oversight, performance measurement and achieving quality outcomes. Comments related to *Community Inclusion and Public Acceptance* addressed community integration and the community-based service system, public relations and culture change. Lastly, comments categorized under *Individual Control and Personal Development* comprised several topics related to the goal of supporting each individual to live the life he or she wants.



Note: Throughout this report, percentages may not total 100% exactly due to rounding.

How Comments Are Counted: Comments were counted once for each instance a topic was discussed at some point in an individual testimony. For example, if a line of testimony read “there should be more opportunities for employment in the community to encourage inclusion,” it was categorized under the topics “community inclusion” and “employment.” A topic was only counted once per testimony no matter how many times it was mentioned or how long it was discussed. For instance, a paragraph written about the benefits of community inclusion, or simply the statement “I support community inclusion” would each count as one comment on that topic for that testimony.

Organizing Comments in a Three-Tier Hierarchy

To organize the voluminous amount of data provided by the public, this analysis arranged the 1,999 comments received in a three-tier hierarchy. For each category of comments, there is a main, high-level category, which is broken into one or more subcategories, which are then further divided into multiple specific topics:

Main Category	Subcategory	Topic
This is a broad, high-level category	A subcategory combines several topics	Topics are the most detailed

Example: For the main category of *Supports and Services*, there are several subcategories, including *Employment & Day Supports*, *Exceptional Populations*, and so on. Within each of these subcategories are additional topics. For example, within *Employment & Day Supports* there is an *Employment/Supported Employment* topic and also other topics like *Day Habilitation* and *Volunteer Activities*:

Main Category	Subcategory	Topic
SUPPORTS AND SERVICES	EMPLOYMENT & DAY SUPPORTS	Employment, Supported Employment
		Day Habilitation
		Volunteer Activities
		Innovative Day Activities
	EXCEPTIONAL POPULATIONS	Children
		High/Complex/Med Needs Individuals
		Autism/ASD
		Behavioral Challenges
		Aging Individuals and Caregivers
		Transition (to OPWDD services)
		Dual Diagnosis

For a complete breakdown of all categories, see *Appendix A: Comments Categorization Hierarchy and Frequency of Response*. This appendix lays out the structure of the hierarchy for all 1,999 comments and indicates the categorization of all comments, with additional percentages included for comparison purposes.

Comment Analysis

- Part 1: Supports and Services -



Within *Supports and Services* are a number of subcategories, as follows:

Subcategory	Number of Comments	% of All Comments Received	% of Comments in Main Category
Employment & Day Supports	119	6.0%	12.2%
Exceptional Populations	180	9.0%	18.5%
Family Supports	101	5.1%	10.4%
Health Supports	48	2.4%	4.9%
Home	121	6.1%	12.4%
Individualized Supports	89	4.5%	9.1%
Staffing	130	6.5%	13.3%
Supports for Community Living	187	9.4%	19.2%
Total	975	48.8%	100.0%

Employment and Day Supports: The majority of responses (72 comments) in this subcategory were on employment and supported employment. The desire for greater access to supported employment opportunities, skills training to prepare for employment, and being a part of the competitive workforce were all noted as priorities. Respondents told OPWDD that the importance of employment in community integration cannot be overstated, nor can the importance of volunteer activities. Opportunities for volunteering in the community were identified as an important source of interaction, growth, and pride. Several respondents requested innovative day activities and noted

desirable models such as “day habilitation without walls,” some of which may require 1:1 support. Noted less frequently were day habilitation, sheltered workshops, and other traditional programs. Comments related to traditional day programs relayed stories of individual success and satisfaction with the programs, although some questioned their effectiveness or efficiency. Supported employment, volunteer activities, and innovative day activities combined were mentioned five times as often as traditional day activities.

Exceptional Populations: This subcategory refers to specific groups or subpopulations of people with developmental disabilities. The most frequently mentioned exceptional population was children, and parents and advocates stressed the needs of children with developmental disabilities for community integration and opportunities for interaction with their non-disabled peers. Parents of children transitioning out of the public school system requested that the individualized planning and integrated services they have often received through the school system continue throughout adulthood with clearly defined paths toward education, employment, housing, relationships, and a meaningful life.

Another frequently mentioned group was those with high needs or medically complex needs. Ensuring resources are available to maintain these individuals' support despite their challenges was a primary concern, as was the continuation of OPWDD's long-standing practice of allocating resources based on individual need. An equal number of responses were received regarding autism, with respondents calling for innovative, person-centered, and clinically sophisticated therapies. One notably thoughtful testimony came from a man with autism who noted that the autonomy he experienced through independent living had helped him grow and overcome the symptoms associated with his disability.

Another major area identified was behavioral challenges, which, like autism, may require special clinical interventions. Respondents noted the complexity and importance of community integration for individuals with behavioral challenges and the importance of in-home and crisis supports to preserve the stability and safety of the individual and their family. Enmeshed in these topics and sometimes

mentioned separately were the challenges of providing services to individuals with dual diagnoses (diagnoses of both a developmental disability and a mental health disorder). Respondents noted difficulties that dually diagnosed individuals have had in navigating multiple systems of care.

One last major topic was aging individuals and caregivers. Aging parents expressed concerns that their now adult children will have nowhere to go but an emergency placement upon the parents' death. They said they want more certainty in understanding what will happen to their loved one in that eventuality. Likewise, they requested residential development to accommodate the needs of their aging children.

Family Supports: This subcategory encompasses comments about a wide array of family needs and concerns. Comments related to Family Support Services ranged from requests for newly-designed services to help keep individuals in the family home to the expansion of supports already covered by the OPWDD Family Supports and Services program. These include family counseling, respite (which is also considered later in this report as a support for community living), family training, and reimbursement of expenses. Training in the proper care of their family members was a prominent concern of families, and counseling to help families work through the challenges they may face was also requested frequently.

Family members also described the stress of caring for their loved ones with disabilities at home. Families collaborating to work together on designing services and supporting each other (e.g., through support groups) were noted as a source of innovation and strength.

Health Supports: Comments related to health supports often referred to concerns felt more acutely by those with serious medical challenges. However, the importance of good health for all individuals is an obvious concern for stakeholders, as well. Respondents requested greater availability of clinical and therapeutic services offered specifically for individuals with developmental disabilities (i.e., via Article 16 clinics). Comments regarding general healthcare included the recommendation that hospital staff be educated about individuals with developmental disabilities and ensuring that resources and training that support good health are available. Several respondents identified crisis supports as critical for the short-term stabilization of individuals with behavioral challenges. Mentioned less frequently (four times) were requests that medication administration rules be revised so that direct care staff can more easily provide medication than current regulations allow and that alternate methods of providing medication be allowed based on individual circumstances.

Home: Many respondents spoke about the homes that individuals reside in, be they supported apartments, homes they have purchased with or without government assistance, or congregate living settings like traditional group homes. Most responses in this category (45 comments) related to expanding the availability of residential opportunities through the construction and certification of new homes.

Requests for the expansion of supported housing demonstrated the diverse needs of the individuals OPWDD supports. Other respondents requested innovative options such as non-certified homes funded through Section 8 subsidies or other means like the OPWDD Home of Your Own program and shared living,

whereby a live-in caregiver is paid for assisting an individual to live in a non-certified setting. Some advocated for group homes, noting that group homes provide needed supervision, structure and safety and that many individuals are satisfied with their group living arrangements.

Respondents also described how natural supports supplement funded supports and empower individuals to live more independently. Environmental modifications and assessments were also indicated as key in helping individuals remain in the family home or move into their own accessible home.

Individualized Supports: Now more than ever, individuals and their families are calling for personalized, individualized support options. Through these options, the system addresses concerns on a person-by-person basis, turning the paradigm of asking an individual to “fit into” programs on its head. Comments in this category referred to the development of individualized services, the use of person-centered planning and implementation of person-centered plans, the importance of self-direction and personal autonomy for individuals, and ensuring that individuals have sufficient information and opportunity to make decisions about the supports they access. Seventy-six comments were received on this topic, making it the second most commonly mentioned topic (after community integration.)

Additionally, 13 more comments were received that specifically mentioned OPWDD’s self-determination program, Consolidated Supports and Services (CSS). These comments praised the program for offering individuals true control over their lives, requested expansion of the program, and suggested simplifying the CSS program procedures.

Staffing: This subcategory received 130 wide-ranging comments related to the direct support professionals (DSPs) who support individuals with developmental disabilities. The majority of comments praised DSPs for the work they do, and also identified areas of specific concern. DSPs spoke at the forums, and declared their commitment to the people they support and the important work they do.

Training was noted many times, with suggestions ranging from making initial trainings more comprehensive by including more information on different disabilities to having DSPs specialize in care for a population of their choice and receive in-depth training in that area. In any case, well trained and capable DSPs were viewed as essential in assuring the quality and effectiveness of the supports delivered.

Wages were another major area of concern, with respondents voicing virtually unanimous agreement that DSPs should be offered better wages and benefits like tuition forgiveness to increase the appeal of the developmental disability field to new college graduates. Comments identified higher wages and a better defined career ladder as key prerequisites to workers viewing their jobs as more of a profession. Retaining DSPs was also frequently mentioned, with respondents describing high turnover among this workforce and the impact of turnover on training investment and the individuals served.

Supports for Community Living: This subcategory refers to a wide array of services which are designed to help people reside in, engage with, and get to know their communities. These services may be delivered in the family home, a group setting, or an individual's supportive housing arrangement.

The most frequently noted support for community living was the need for respite. Respite is a service in which a worker temporarily takes over the responsibility of caring for an individual so that the regular caregivers (e.g., their family members) can take a break. Parents noted repeatedly the need for greater availability of respite and for respite to be provided for longer periods of time (i.e., not on an hourly basis). They noted that today, it is difficult to access respite for multiple consecutive days, which makes focusing on a project (like home repairs) or taking a vacation very difficult for the primary in-home caregiver.

Respondents also noted that transportation was another concern, and that engaging in activities in the community like working, attending classes, or participating in recreational activities is often impossible without transportation. A taxi-style service available to individuals with developmental disabilities and instruction on the use of public transit were both suggested.

Another area families and individuals said was particularly important was providing opportunities for recreation and social interaction. They noted that activities that are solely for individuals with developmental disabilities and activities that are for both those with and without disabilities are important to personal growth. The latter is also important to community acceptance and inclusion. These activities were described as key to having a balanced life.

Respondents also noted that community and residential habilitation are important services. In particular, numerous respondents requested additional community habilitation and noted that the basic living skills provided through residential habilitation are an important foundation for individuals with developmental

disabilities to build upon. The preservation of homecare services and their importance in allowing supported living were also mentioned by several respondents. These services provide a typically lower level of care to individuals who live independently in the community. Nonetheless, they provide assistance that is essential for the individual to function in daily life. As one self-advocate noted, going to work is impossible if you are physically unable to get out of bed in the morning! In addition, respondents noted the need to expand after-school programs

and provide easier access to durable medical equipment.

One last area mentioned by several respondents was the success of the New York State service system in moving from an institutionally-based model to one which supports people to live independently in the community. Many stories of personal success and happiness were described throughout the People First Waiver forums. These stories serve as reminders of what people with developmental disabilities are capable of and what can be accomplished.

- Part 2: Access and Funding-



Subcategory	Number of Comments	% of All Comments Received	% of Comments in Main Category
Access	135	6.8%	30.5%
Administrative Processes	110	5.5%	24.8%
Breaking Down Silos	26	1.3%	5.9%
Funding	92	4.6%	20.8%
Service Coordination	80	4.0%	18.1%
Total	443	22.2%	100.0%

Access: Respondents identified concerns regarding the availability of services, which may be impacted by a variety of factors including available staffing, geographic limitations, and adequacy of resources. Common topics were access to supports and services (54 comments), fiscal pressure or funding impacts on service availability, and the process of determining one's eligibility for services.

Gaining access to services was noted as a potentially complicated and extensive process. Respondents requested a streamlined eligibility process and a single application for services. Several respondents also voiced concern that existing services and eligibility for current services must be maintained for those individuals receiving them throughout any transition associated with the People First Waiver. Several people also commented regarding the assessment of individuals' needs and the instrument used to conduct the assessment, noting that individuals must be assessed appropriately and correctly.

In addition, respondents noted that it is important for families to be provided clear information about the service options for individuals entering the system and how the enrollment process works.

Administrative Processes: The majority of comments in this subcategory referred to the need to streamline paperwork and administrative functions. Respondents told us that too much time is devoted to paperwork. They suggested that OPWDD use a single application for all OPWDD services, require less frequent updates to plans and documents, and develop simpler processes. Another concern was the amount of training staff must undergo in order to be able to complete documentation.

Many respondents suggested using technology and electronic medical records to avoid duplication and facilitate communication. Some suggested the development of a single point of access for information related to an individual's care and support such as a secure website "portal," which could be accessed from any

computer with Internet access. In addition, some suggested that OPWDD develop incentives for motivating agency performance and rewarding agencies that provide quality services, are fiscally responsible, and pursue new courses of development encouraged by OPWDD. They said that this would help ensure quality and spur change.

An equal number of comments (13 for each topic) suggested the need for regulatory reform and privatizing services. Regulatory reform was primarily requested to reduce the cost of meeting mandates and remove barriers to the development of innovative services.

Respondents who requested the privatization of services suggested that services can be provided at less cost by voluntary agencies with strong records of success.

Several respondents noted the importance of transparency in administrative decisions and the need for technical assistance for agencies as they implement administrative changes.

Breaking Down Silos: The term “administrative silo” refers to a lack of communication or common goals between departments in an organization or between different service systems. Forum respondents spoke to three distinct forms of collaboration that are needed to address current system silos. The first is cross-systems collaboration between OPWDD and other New York State agencies such as the Office of Mental Health (OMH) and State Education Department (SED). Stronger alliances of this kind would be of benefit, in this example, to individuals who are dually diagnosed with both a developmental and mental health disability and children who are transitioning from public schools to the OPWDD service system.

Respondents also suggested that developing public-private partnerships between OPWDD

and community entities would result in greater opportunities for individuals outside the regular OPWDD service delivery system. For example, partnerships with community organizations could offer recreational and social opportunities for individuals, while partnering with businesses interested in hiring individuals with developmental disabilities could lead to their meaningful employment. One last level of collaboration requested was between service providing agencies, whereby among voluntary agencies coordinate operations and share resources to provide comprehensive care and fill existing gaps in service provision.

Funding: The vast majority of comments related to funding revolved around fiscal responsibility and agency use of public funds. Individuals and families requested more control over the funds allocated on their behalf, including the development of personalized budgets. Respondents noted that there was a need for additional funding, but also that the use of resources should be reviewed to determine whether savings could be found through efficiencies. Funds reclaimed in this manner could then be directed to service provision.

Respondents also voiced concern that they cannot be sure that funds dedicated to program areas do in fact go to those areas and do not support increased overhead costs. A number of respondents suggested redirecting and reinvesting existing resources to more desirable or emphasized program areas. They also noted that complexity in billing and funding require time and effort to be spent on paperwork and training staff how to complete that paperwork instead of going directly into providing a service to the individual.

Comments regarding the managed care model included cautions that the model be applied

carefully and appropriately to individuals with developmental disabilities. Respondents noted the need to ensure that the allocation of resources continues on the basis of need.

Also mentioned was the notion of cost-sharing by families to provide funding beyond what is offered by the State. Family collaboration on innovative residential projects, for example, was noted as a way for families to work together to design and coordinate services. Lastly, a handful of respondents suggested that vouchers for community organizations would be a simple way to allow individuals to access opportunities not formally linked to the OPWDD system (for example, funds to defray the costs of an art program available to the general public).

Service Coordination: Numerous respondents also noted service coordination as an important

support to families as they seek to learn about and access different service options. They said it was important for service coordinators to be well trained and have manageable caseloads. This allows the service coordinator to inform families about appropriate support options for an individual and gives them time to link the individual to the supports they want and need. Respondents told us that the coordination of services enables successful community living by facilitating and ensuring the delivery of appropriate and quality supports in a community setting.

Additionally, families requested more support to help them assess and decide which services are best for their loved ones and opportunities for more involvement and engagement in the service design process.

- Part 3: Quality -

	Number of Comments	% of All Comments Received
Quality	217	10.9%

The quality theme spans many areas which are closely interrelated and is considered as one category (with no further breakdown into subcategories). Well over half of all the comments received regarding quality centered on gathering feedback from individuals and families, performance measurement, and improving outcomes and the quality of services in general. Out of the 217 comments received in the quality category, about 140 comments referred to one of these three topics.

The most common comments related to quality were in response to forum question #4, which asked respondents what OPWDD should be measuring to determine its effectiveness. A resounding answer to that question was to ask individuals and families what they need and then assess agency performance in meeting those goals. Many people suggested that OPWDD and its providers survey individuals and families about individual outcomes and how well their services meet their needs and desires.

Closely following this topic and inextricably linked were suggestions from agency representatives, families, and other stakeholders for OPWDD to use performance measurement as a way of developing quality services and ensuring that agencies are in fact performing at an acceptable level. Suggestions for performance metrics included making information available regarding the performance

of multiple agencies (i.e., how they compare to each other), relying on standardized measures to objectively measure performance, and empowering agencies to work with stakeholders to develop their own internal metrics.

People also offered comments regarding improving outcomes for individuals served by the system. Respondents suggested that quality objectives should be crafted in consultation with the individual and their family. They noted that families should be provided appropriate information on the range of options before them, with the individual's progress monitored regularly. Respondents told us that an inability to attain outcomes should spark a review of the service plan and adjustments where needed. They also noted that rather than providing services which simply maintain an individual, the delivery system should work with those served to ensure they are receiving productive support that allows them to reach their full potential.

Another aspect of quality that respondents noted was oversight and quality assurance, both of which were stressed as critical in ensuring people's confidence and stability in the system. Respondents recommended that strong and consistent oversight is a prerequisite to all other aspects of quality. Similarly, they stressed that ensuring safety is a critical concern. Noted less frequently were concerns over abuse, accountability, and OPWDD's provision of

specific standards of care to guide the work being performed on behalf of the individuals served.

Two other quality concerns arose, albeit less frequently. The first was for consistency of service, which was pointed out as essential to maintaining stability in a person's life. Lastly,

respondents also noted the uniqueness of the developmental disability community. They told us that the exceptional gifts and talents of individuals with developmental disabilities can only be developed within a system of care that directly addresses the diverse needs of this unique group.

- Part 4: Community Inclusion and Public Acceptance -

	Number of Comments	% of All Comments Received
Community Inclusion and Public Acceptance	214	10.7%

Like quality, this category lends itself to considering all 214 comments together. Most notably, the topic of community services and integration was mentioned more often than any other topic (92 comments). These explicit mentions were supplemented by many implicit references to lives that involve community support and immersion. The near universal mention of this topic indicates a strong and determined movement that celebrates the accomplishments of the OPWDD system in deinstitutionalization, affirms a commitment to community supports, and seeks to refine and expand upon past accomplishments. Suggestions included not only the expansion of community support options, but also changing attitudes about and perception of developmental disabilities both within the service system and among the general public.

Individuals, family members, and the agency staff and advocates that support them affirmed that the community is the right place for individuals with developmental disabilities. They noted that communities must be encouraged to be inclusive, and that individuals with developmental disabilities need only the appropriate support to contribute to their communities in a meaningful way, whether through paid employment, singing in the church choir, or simply offering a smile to a neighbor. The range of diverse talents, gifts, and positive attributes offered by individuals with

developmental disabilities can only be fully expressed in an accepting and inclusive community.

The second most commonly noted topic (receiving 48 comments) in this category noted the need for a change in attitudes and culture. Forty-four additional comments were related to OPWDD communications and public relations. These two numbers taken together equal the number of comments received regarding community integration (92 comments), demonstrating the importance of this area to stakeholders. Respondents told us that for an individual to succeed in the community, appropriate support for community integration must be provided and the community must understand and welcome individuals with developmental disabilities. Concerns over alleviating public misconceptions about individuals with developmental disabilities were voiced many times, with frequent suggestions for OPWDD to work with public schools to offer sensitivity awareness training and to provide public service announcements to let people know that individuals with developmental disabilities are a valuable part of their communities.

Respondents also discussed institutional services, expressing gratitude and pride at moving OPWDD's service system away from an institutionally based system. Still others

suggested that some individuals with particular behaviors cannot be appropriately supported in the community and may require a form of institutional care. They cautioned that some institutional capacity should be maintained to stabilize individuals who are in crisis or at risk of entering the criminal justice system, but that these institutional supports for behavioral stabilization should be short-term in nature.

Some also mentioned the need for OPWDD to serve individuals in the least restrictive setting appropriate for them, per the Olmstead ruling. Lastly, respondents noted the isolation experienced by individuals in and outside of the community and the importance of supports like respite and transportation in preventing such isolation.

- Part 5: Individual Control and Development -

INDIVIDUAL AND FAMILY CONTROL

PERSONAL GROWTH

Subcategory	Number of Comments	% of All Comments Received	% of Comments in Main Category
Individual and Family Control	77	3.9%	51.3%
Personal Growth	73	3.7%	48.7%
Total	150	7.5%	100.0%

Individual and Family Control: The most frequently mentioned topic in this subcategory was individual and family choice over the “who, where, when, and how” of their services: who will provide the support, where the support will be offered, when the support will be available, and how the support will be delivered. Individuals and families expressed that they want to be part of each of these decisions and be provided the tools and information necessary to make informed, judicious choices. Respondents also noted that having flexibility to adapt these aspects of service delivery to changing circumstances is important to them. Agency representatives, individuals, families, and advocates noted that existing barriers within the service system, many related to billing, constrain their ability to design and experience innovative services. The People First Waiver is viewed as a way to get beyond this inflexibility.

Respondents also suggested that the funding available for an individual be made clear on a per-person basis and that personal and portable budgets be developed. Lastly, respondents suggested that respecting the civil rights and

citizenship of individuals with developmental disabilities requires integrated services and individuals to be involved in decision-making regarding the supports they receive.

Personal Growth: Respondents noted relationships and friends as being the key to personal growth and a meaningful life. They said that opportunities for social interaction with disabled and non-disabled peers and support for interacting in an appropriate way are important in the development of these bonds. They noted that obtaining skills and continued learning are important facets of socialization, independent living and obtaining employment. Likewise, respondents stressed that it is important to provide college and educational opportunities for individuals whose goals include post-secondary education. They noted that self-advocacy is important for personal growth and suggested that additional resources and effort be directed at empowering individuals to recognize their ability to make choices and have a say in their service delivery. They told us that supporting self-esteem builds confidence and individual success.

Topics Most Commonly Noted

The table below reports topics which received 30 or more comments. The counts for all topics can be found in Appendix D.

Topic	Number of Comments
Community Services, Integration	92
Individualized Services/Person-Centered Planning/Self-Direction	76
Employment, Supported Employment	72
Family Support Services	62
Respite	59
Survey Individuals/Families	56
Access	54
Performance Measurement	53
Attitudes & Culture Change	48
Children	47
Direct Support Professionals	46
Residential Requests, Development	45
Communication, Public Relations	44
Service Coordination	42
Streamlining Paperwork, Administration	42
Family Support/Involvement to Assess/Design Services	38
Lowering Costs, Fiscal Responsibility	37
Direct Support/Staff Training	36
Transportation	36
Outcomes, Improved/Quality	34
Choice, Individual and Family	31
High/Complex/Medical Needs Individuals	31
Fiscal Pressure, Funding	30

Conclusion

The feedback provided at the People First public forums pertained to nearly every aspect of the service system imaginable. Each person approaches the system with different concerns and at a different point in their lives. We find middle aged or elderly individuals just entering the service system, young adults transitioning to the OPWDD system from school and home, and the parents of infants and toddlers with autism or other disabilities—each with different needs, expectations, and abilities.

What is common among all of these groups is the need for individualized support delivered in a caring way by professionals specializing in the diverse field of developmental disabilities. It is OPWDD's challenge and charge to build upon a proud tradition of deinstitutionalization, community integration, and high-quality services to provide this kind of support to these diverse individuals in ways that work best for them. That is the challenge of the People First Waiver, and it is clear OPWDD's stakeholders are engaged and ready to help build the service system of tomorrow.

Thank you to everyone who submitted testimony. The testimony received reflected a great deal of time, effort, and thoughtful consideration of the important questions and issues presented for comment by OPWDD. While the full detail of each comment cannot be recounted in a summary report like this one, respondents should know that all testimony received was carefully reviewed in full.

OPWDD thanks our constituents and partners in the People First Waiver design process—individuals with developmental disabilities, their parents, siblings, and other family members, the provider agencies and advocacy groups that support them, and countless others—for their continued support in developing the People First Waiver and for everything you do on behalf of people with developmental disabilities.

Appendix A: Comments Categorization Hierarchy and Frequency of Response

Total comments received: 1,999

Total Respondents: 251

Average Comments/Respondent: 8.0

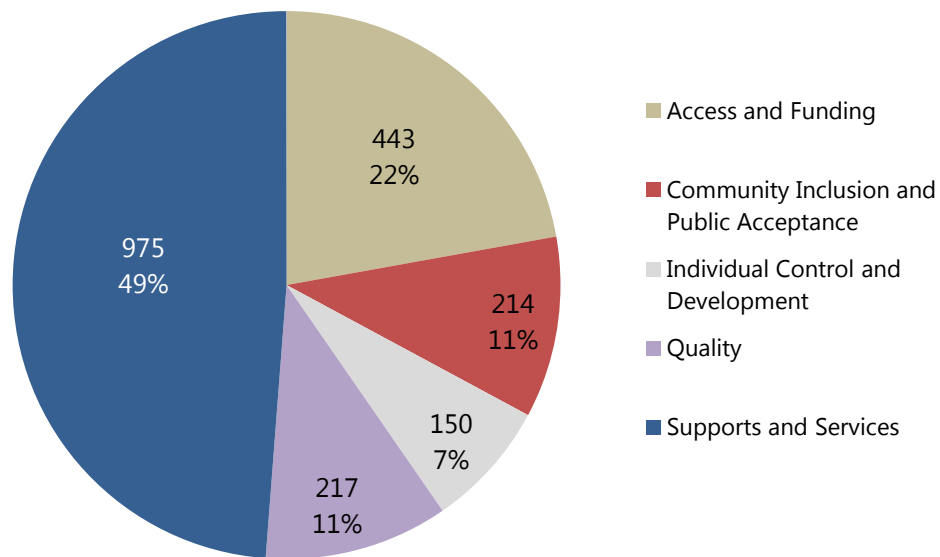
USING THIS CHART – DEFINITION OF ELEMENTS								
Main Category	Category Total	Overall %	Subcategory	Subcat. Total	Subcat % of Total	% Within Main Category	Topic	Topic Total
This is a broad, high-level category	# of comments received for the main category	% of comments in this main category out of total	A subcategory combines several topics.	# of comments received for the sub-category.	% of comments in the sub-category out of all comments	% of comments in this sub-category out of the comments received in its main category	Topics offer the greatest detail	# of comments on the topic

Main Category	Cat. Total	Over-all %	Subcategory	Subcat Total	Subct % Ttl	% W/in Mn cat.	Topic	Tp. Ttl
ACCESS AND FUNDING	443	22.2%	ACCESS	135	6.8%	30.5%	Access	54
							Fiscal Pressure, Funding	30
							Eligibility/Approval Process	24
							Maintain Existing Services (Eligibility)	14
							Assessment of Individuals	11
			ADMINISTRATIVE PROCESSES	110	5.5%	24.8%	Low/Mild Needs Individuals	2
							Streamlining Paperwork, Administration	42
							Technology, Use of	18
							Incentives (for Agency Performance)	14
							Privatizing Services	13
							Regulatory Reform	13
							Transparency	6
							Technical Assistance	4
			BREAKING DOWN SILOS	26	1.3%	5.9%	Cross-Systems Collaboration	13
							Public-Private Partnerships	8
							Collaboration, Agency	5
			FUNDING	92	4.6%	20.8%	Fiscal Responsibility	37
							Agency Use of Public Funds	15
							Redirecting Funds	10
							Complexity in Billing/Funding	7
							Family Subsidized Services (cost sharing)	7
							Managed Care Model	7
							Rational Reimbursement Mdl.	3
							Reinvesting Resources	3
							Vouchers for Community Organizations	3
			SERVICE COORDINATION	80	4.0%	18.1%	Service Coordination	42
							Family Support/Involvement to Assess/Design Services	38
COMMUNITY INCLUSION AND PUBLIC ACCEPTANCE	214	10.7%	COMMUNITY INCLUSION AND PUBLIC ACCEPTANCE	214	10.7%	100.0%	Community Services, Integration	92
							Attitudes & Culture Change	48
							Communication, Public Rltns	44
							Institutional Settings	14
							Least Restrictive Settings	10
							Isolation	6
QUALITY	217	10.9%	QUALITY	217	10.9%	100.0%	Survey Individuals/Families	56
							Performance Measurement	53
							Outcomes, Improved/Quality	34
							Oversight, Quality Assurance	26
							Safety	24
							Abuse	8
							Consistency	5
							Accountability	4
							Uniqueness of DD Community	4
							Standards of Care	3

Main Category	Cat. Total	Over-all %	Subcategory	Subcat Total	Subcat % Ttl	% W/in Min cat.	Topic	Tp. Ttl
SUPPORTS AND SERVICES	975	48.8%	EMPLOYMENT & DAY SUPPORTS	119	6.0%	12.2%	Employment, Supported	72
							Day Habilitation	20
							Volunteer Activities	16
							Innovative Day Activities	11
			EXCEPTIONAL POPULATIONS	180	9.0%	18.5%	Children	47
							High/Complex/Med Needs Individuals	31
							Autism/ASD	29
							Behavioral Challenges	26
							Aging Individuals and Caregivers	23
							Transition (to OPWDD services)	18
							Dual Diagnosis	6
							Family Support Services	62
			FAMILY SUPPORTS	101	5.1%	10.4%	Family Training	17
							Family Stress	16
							Collaboration, Family	6
							Health	16
			HEALTH SUPPORTS	48	2.4%	4.9%	Crisis Supports	15
							Clinical/Therapeutic Services	13
							Medication Administration	4
							Residential Requests, Development	45
			HOME	121	6.1%	12.4%	Group Homes, IRAs	24
							Apartments & Housing, Supported	22
							Environmental Assessments/Modifications	12
							Non-Certified Homes	10
							Natural Supports	4
							Shared Living	3
							Family Care	1
			INDIVIDUALIZED SUPPORTS	89	4.5%	9.1%	Individualized Services/Person-Centered Planning/Self-Direction	76
							Consolidated Supports and Services	13
			STAFFING	130	6.5%	13.3%	Direct Support Professionals	46
							Direct Support/Staff Training	36
							Direct Support Wages	23
							Direct Support Retention	18
							Direct Support Staff, Certified	7
			SUPPORTS FOR COMMUNITY LIVING	187	9.4%	19.2%	Respite	59
							Transportation	36
							Recreation/Social Opportunities	27
							Community Habilitation	22
							Home Care Services	15
							Success of NYS System/Services	13
							Residential Habilitation	7
							After School Programs	6
							Durable Medical Equipment	2
							Choice, Individual and Family	31
INDIVIDUAL CONTROL AND DEVELOPMENT	150	7.5%	INDIVIDUAL & FAMILY CONTROL	77	3.9%	51.3%	Flexibility	25
							Budgets, Personal Control/Portable	17
							Civil Rights, Citizenship	4
							Relationships, Friends	25
			PERSONAL GROWTH	73	3.7%	48.7%	Skills, Learning	19
							Self-Advocacy	10
							Education, College	9
							Personal Growth	7
							Self-Esteem	3

Appendix B: Main Categories Pie Chart and Table

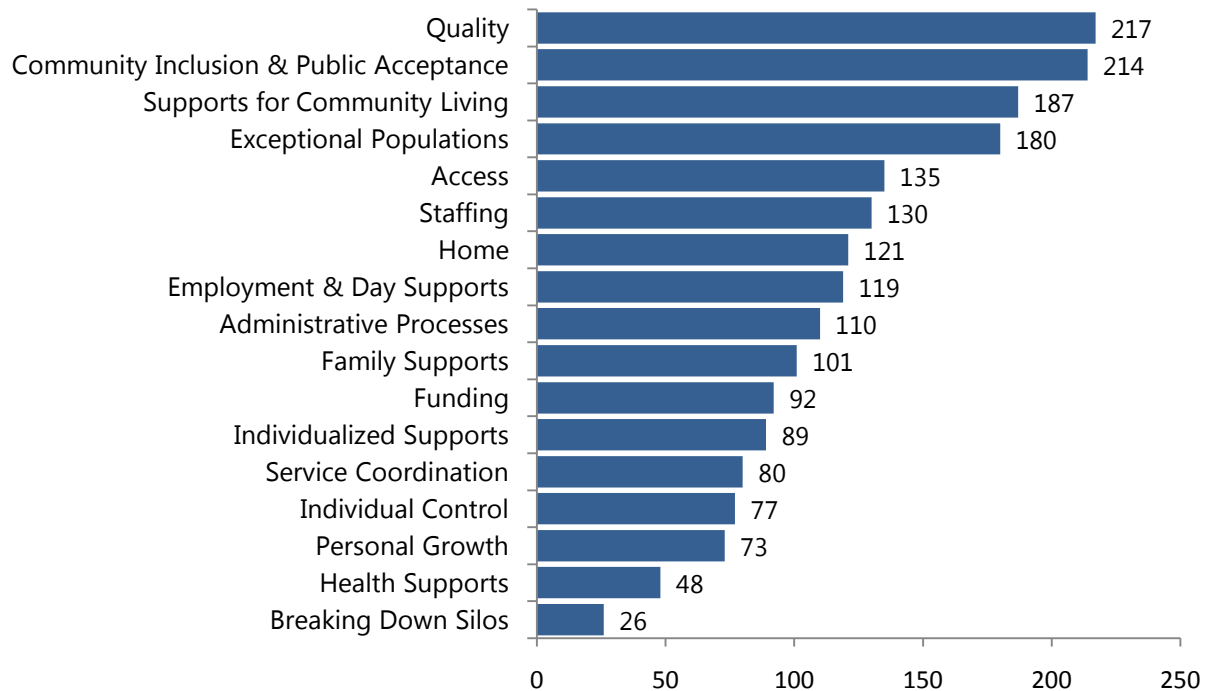
Number and Percentage of Comments Received for Each Main Category, N=1,999



Main Category	Comments Received	% of Overall Comments Received
Supports and Services	975	48.8%
Access and Funding	443	22.2%
Quality	217	10.9%
Community Inclusion and Public Acceptance	214	10.7%
Individual Control and Development	150	7.5%
All Categories	1,999	100.0%

Appendix C: Subcategories Chart and Table

Number of Comments Received for Each Subcategory in Rank Order, N=1,999



Subcategory	Comments Received	% of Overall Comments Received
Quality	217	10.9%
Community Inclusion & Public Acceptance	214	10.7%
Supports for Community Living	187	9.4%
Exceptional Populations	180	9.0%
Access	135	6.8%
Staffing	130	6.5%
Home	121	6.1%
Employment & Day Supports	119	6.0%
Administrative Processes	110	5.5%
Family Supports	101	5.1%
Funding	92	4.6%
Individualized Supports	89	4.5%
Service Coordination	80	4.0%
Individual Control	77	3.9%
Personal Growth	73	3.7%
Health Supports	48	2.4%
Breaking Down Silos	26	1.3%
All Subcategories	1,999	100.0%

Appendix D: Topics in Rank Order, N=1,999

(The table displays the name of each topic and the number of comments received for that subcategory.)

Community Services, Integration	92	Institutional Settings	14
Individualized Services/Person-Centered Planning/Self-Direction	76	Maintain Existing Services (Eligibility)	14
Employment, Supported Employment	72	Privatizing Services	13
Family Support Services	62	Regulatory Reform	13
Respite	59	Cross-Systems Collaboration	13
Survey Individuals/Families	56	Clinical/Therapeutic Services	13
Access	54	Consolidated Supports and Services	13
Performance Measurement	53	Success of NYS System/Services	13
Attitudes & Culture Change	48	Environmental Assessments/Modifications	12
Children	47	Assessment of Individuals	11
Direct Support Professionals	46	Innovative Day Activities	11
Residential Requests, Development	45	Redirecting Funds	10
Communication, Public Relations	44	Least Restrictive Settings	10
Streamlining Paperwork, Administration	42	Self-Advocacy	10
Service Coordination	42	Non-Certified Homes	10
Family Support/Involvement to Assess/Design Services	38	Education, College	9
Fiscal Responsibility	37	Public-Private Partnerships	8
Direct Support/Staff Training	36	Abuse	8
Transportation	36	Managed Care Model	7
Outcomes, Improved/Quality	34	Complexity in Billing/Funding	7
Choice, Individual and Family	31	Personal Growth	7
High/Complex/Med Needs Individuals	31	Family Subsidized Services (cost sharing)	7
Fiscal Pressure, Funding	30	Direct Support Staff, Certified	7
Autism/Autism Spectrum	29	Residential Habilitation	7
Recreation/Social Opportunities	27	Transparency	6
Oversight, Quality Assurance	26	Isolation	6
Behavioral Challenges	26	Dual Diagnosis	6
Flexibility	25	Collaboration, Family	6
Relationships, Friends	25	After School Programs	6
Safety	24	Collaboration, Agency	5
Eligibility/Approval Process	24	Consistency	5
Group Homes, IRAs	24	Technical Assistance	4
Aging Individuals and Caregivers	23	Civil Rights, Citizenship	4
Direct Support Wages	23	Accountability	4
Apartments & Housing, Supported	22	Uniqueness of DD Community	4
Community Habilitation	22	Medication Administration	4
Day Habilitation	20	Natural Supports	4
Skills, Learning	19	Rational Reimbursement Model	3
Technology, Use of	18	Reinvesting Resources	3
Transition (to OPWDD services)	18	Vouchers for Community Organizations	3
Direct Support Retention	18	Self-Esteem	3
Budgets, Personal Control/Portable	17	Standards of Care	3
Family Training	17	Shared Living	3
Volunteer Activities	16	Low/Mild Needs Individuals	2
Family Stress	16	Durable Medical Equipment	2
Health	16	Family Care	1
Agency Use of Public Funds	15		
Crisis Supports	15		
Home Care Services	15		
Incentives (for Agency Performance)	14		