



NEW YORK
**ALLIANCE FOR
INCLUSION & INNOVATION**

Strength Together

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Testimony to Joint Fiscal Committees of the New York State Legislature

2020-21 Executive Budget for the NYS Office for People With Developmental Disabilities

Mental Hygiene Budget Hearing
Monday, February 3, 2020
Legislative Office Building
Albany, New York

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STRONGER TOGETHER





OPENING

Good morning/afternoon Chairwoman Krueger, Chairwoman Weinstein, Chairwoman Gunther, Chairman Carlucci and distinguished members of the New York State Legislature. Thank you for the opportunity to provide you with our perspective on the 2020-21 Executive Budget as it relates to supports and services to people with disabilities and also the administration of New York's Medicaid program.

INTRODUCTION

The NY Alliance is a statewide association representing nearly 175 not-for-profit agencies serving people with disabilities. Our association envisions a society where people with disabilities are contributing citizens with equal rights and the ability to live full, productive and meaningful lives.

I will focus my testimony on the Executive Budget proposal as it relates to:

- recommendations to address **workforce shortages** faced by the intellectual and developmental disabilities (I/DD) sector
- the **fiscal sustainability** of New York's not-for-profit provider agencies;
- the importance of **transparency with Medicaid redesign** efforts and
- ensuring the successful **transition to managed care** in the I/DD sector.

GENERAL OVERVIEW

On behalf of the NY Alliance, I'm pleased the budget proposal for the NYS Office for People With Developmental Disabilities (OPWDD) once again includes investments to support:

- wage increases for direct support professionals and clinical staff across the mental hygiene sector;
- new and ongoing housing initiatives and service opportunities;
- training and technical assistance for managed care readiness.

We support these investments and applaud the Governor for prioritizing the supports and services that are critical to meeting the needs of people with disabilities.



INVESTMENTS IN THE WORKFORCE

Living Wage for Direct Support

On behalf of the NY Alliance, I'd like to take this opportunity to thank members of the Legislature and the Governor for your consistent support of the campaign to implement a living wage for direct support professionals, direct care workers and clinicians across the three disabilities sectors.

This partnership between government and the not-for-profit sector is one that is critical to the health and well-being of people with disabilities, the staff who support them, the agencies delivering the services, and the overall economy of the State.

We are therefore grateful the Governor maintains the commitment to the direct support workforce in the Executive Budget by including funds to support wage increases effective April 1, 2020 and ask you for your ongoing support of these important funds.

Direct Support Professional Credential Pilot Program

In 2015, the Legislature and Governor Cuomo charged OPWDD to provide recommendations for the design and implementation of a New York State-specific Direct Support Professional Credential Program. The research in the report states that credentialing programs provide targeted educational opportunities that help people master increasingly specialized or rapidly changing content areas in professions without necessarily investing in a longer-term degree program. Credentialing also:

- improves the quality outcomes and affordability of long-term supports and services;
- attracts applicants into the direct support professional field with the potential to decrease turnover and vacancy rates;
- enhances competence in the field;
- yields more quality supports and services to people with I/DD; and
- advances health and safety requirements set forth by the State of New York.

The Assembly and Senate have consistently recognized the importance of the Direct Support Professional workforce and the tremendous value placed on training and career advancement. Legislation currently sponsored by Chairwoman Gunther (A.2077) and Chairman Carlucci, (S.3757), will advance the credential pilot program. On behalf of the NY Alliance, we thank you for your ongoing support of this legislation.



As it will require funding to support the credentialing program, we recommend the Legislature invest \$1.5 million as part of the 2020-2021 Enacted Budget to implement the professional credential pilot program for direct support professionals in the I/DD field. This investment will build upon the use of existing core competencies, skills building, and other educational resources. The funds would support the credentialing of over 300 direct support professionals in this pilot program; and, coupled with the wage enhancements in the proposed budget, begin to address the structural fix needed to support recruitment and retention of workforce in the I/DD field.

FISCAL SUSTAINABILITY OF NEW YORK'S HUMAN SERVICES SECTOR – SUPPORT THE 3 FOR 5 CAMPAIGN

Over the past several years, the State's human services sector has highlighted the need for consistent funding increases to help provider agencies keep up with the cost of doing business. Historically, the sector had received annual cost of living adjustments to ensure that not-for-profit agencies were able to address expenses associated with inflation. Rates to provide services were adjusted to reflect increased costs in food, utilities, fuel, labor, and other necessary products and services as a result of doing business.

As you're aware, the not-for-profits who provide supports and services to New Yorkers with disabilities have been asked to do more with less. Support more people; support more people with more significant/intense needs; provide more compensation to their workforce; accommodate more overtime and new staff training costs that result from lack of investment in the workforce; comply with more regulations and mandates; and invest more in their organizational infrastructure necessary to operate efficiently in a fast-paced/technology based world. All with reduced resources; or, in the best-case scenario, with resources that have remained flat, despite cost escalators that the State accommodates in its own State-operated system and budgets. The fiscal sustainability of some of our member agencies, from all parts of New York State, is in question.

Therefore, the NY Alliance, in conjunction with NY Disability Advocates as members of the 3 for 5 Campaign, call upon the State to commit to an annual investment of 3% for the next five years in the systems that comprise NY's human services sectors, including those organizations that support people with disabilities. It is simply unrealistic to expect these sectors to meet the demands of government for higher quality supports and services when resources to ensure sustainability haven't been realized.

Right now, critical community services are in jeopardy. Over the last decade, provider organizations have received only one cost-of-living funding increase—of just 0.02 percent—and have experienced \$2.6 billion in cuts, pushing many provider agencies to the brink of insolvency.



In a Statewide survey that we conducted, nearly half of providers have less than 40 days of cash on hand. A third of providers reported having to reduce services or cut community programs completely in the last three years due to funding constraints—impacting almost 50,000 New Yorkers with intellectual and developmental disabilities and more than 30,000 employees who support these individuals. In communities across New York, providers are operating with minimal or outdated technology and deteriorating infrastructure. We must stabilize, transform and ensure the future viability of the voluntary service delivery sector – the backbone of the OPWDD service system on which individuals with disabilities and their families rely.

STAKEHOLDER INPUT & TRANSPARENCY WITH MEDICAID REDESIGN TEAM EFFORTS

The second iteration of the Medicaid Redesign Team (MRT) will be organized to advance recommendations to achieve \$2.5 billion in State share savings to the Medicaid program. The task force will build upon the efforts of the original MRT to identify additional efficiencies as well as eliminate fraud, waste and abuse within the system.

Our association feels very strongly that efforts to promote efficiencies in the Medicaid program and eliminating fraudulent activity are key to the integrity of the program. Adequate oversight of the program is a proper way to combat fraud, waste and abuse. However, we caution that overzealous auditing practices for the sole purpose of achieving either a cost savings or to fill a gap in the Medicaid budget is an inappropriate way to realize savings, may cost more money in audit time spent, and ultimately hurts individuals being served, their families, and taxpayers with long-term.

We call upon the Governor and the State Legislature to ensure that the MRT II:

- consists of a cross sector of representatives from all Medicaid covered populations and stakeholders including providers, advocates and family members;
- holds public informational sessions, across the entire State, to allow for ample stakeholder input as to the public's ideas on the second round of New York's redesign of Medicaid;
- allows for ample stakeholder review of Medicaid redesign recommendations while in draft form and well before implementation; and
- hosts public informational sessions with specific populations subject to recommendations.

We further urge the Governor and the Legislature to ensure that mechanisms are in place so that future Medicaid audits do not replicate those in the early 2010's where providers were subject to



intensive scrutiny, extensive amounts of time and findings that resemble audits previously completed, misrepresentations of documents and unfair practices where mistakes and clerical errors were deemed fraud and abuse in an attempt to recoup funds for the sole purpose of filling a budget gap.

Lastly, we urge legislators and committees with oversight and responsibility for the Department of Mental Hygiene agencies to pay close attention to the MRT II process for any potential impacts on the populations served by these agencies – both intended and unintentional.

MEDICAID MANAGED CARE TRANSITION

Ensuring Adequate Resources for the Transition:

We all agree that managed care should not result in a reduction in supports and services due to lack of availability of needed programs, unreasonable utilization review criteria, or a diversion of current financial supports for services to pay for the cost of implementing managed care. Instead, managed care should enhance inclusion, person-centered planning, and equity in access to health care and DD services.

The key to achieving this goal is an effective care coordination model that will move us beyond the "silo" approach to accessing services and help families and people with disabilities access supports across multiple systems. Furthermore, under the current fee-for-service system, a significant number of providers are in jeopardy of failing. Managed care should enhance, not jeopardize, the financial viability of providers. Otherwise, there is a real danger that people with disabilities and families in all parts of New York will not be able to access services. The State must recognize that managed care implementation in all other sectors has exacerbated pre-existing financial pressures on providers, not alleviated them. Therefore, it is imperative to first address financial vulnerabilities in the system, not the least of which is the ability of providers to pay Direct Support Professionals a living wage.

As part of the transition to managed care, the State should guarantee that the resources needed to stand up a managed care delivery system are not taken out of services and supports for people with disabilities and their families. Under no circumstances should the administrative costs associated with managed care come out of services and supports. Providers, let alone the families and individuals with disabilities they support, cannot sustain the estimated \$500M to \$800M in service reductions that will be required to implement managed care.



Health Information Technology

One of the key areas to ensure that managed care can be operationalized for people with I/DD, is through the use of modernized health information technology or HIT. HIT supports the health information management across computerized systems and enables the secure exchange of an individual's health information between providers, managed care organizations and other payers. Electronic health records are one example of HIT currently used by many providers but not necessarily all providers as we've found through the managed care readiness self-assessment of the readiness project. The use of HIT varies widely across all sectors including I/DD and many are well versed in its applications while others continue to use antiquated systems that will not allow a provider to engage with managed care entities.

Even with appropriate HIT systems in place, provider agency staff need to be adequately trained on the use of new and innovative systems. Therefore, investments are required to enable providers to modernize the delivery of truly person-centered supports and services as well as timely reimbursement. Start-up funds are necessary for the purchase, training, and optimal use of health information technology for provider agencies. Ongoing resources are also necessary to use, enhance and optimize the system.

NY Alliance for Inclusion & Innovation – Managed Care Provider Readiness Education and Technical Assistance Initiative

Based on conversations with different stakeholders within the field, it's clear that most of the individuals and families served and supported by the I/DD system do not have a clear understanding of why the state is transitioning to managed care and what the benefits might be for people with I/DD. While some express a limited understanding of how managed care may be helpful, many don't understand the potential benefits of moving the fee-for-service system into Medicaid managed care. Likewise, providers require ongoing technical assistance and training for the transition and implementation stages of managed care.

In 2018, the New York Alliance launched a technical assistance project to provide training and educational opportunities on managed care readiness which will enable I/DD providers to leverage their strengths as agencies transition to managed care. This project, the Managed Care Community of Practice (MCCOP), is available to all I/DD providers throughout the state.

We're grateful to the Legislature for providing the New York Alliance with funds in the 2018-2019 Enacted Budget to launch this important initiative and we're pleased at the success to date. The 2020-2021 Executive Budget maintains an investment in resources for the MCCOP to continue to improve provider readiness for managed care through the ongoing development of



training and tools, and to identify and implement best practices, performance measurement and outcome monitoring tools.

Along with a team of professional consultants well versed in Medicaid and Medicaid managed care, the MCCOP has held a series of educational presentations on key areas such as:

- The basic concepts associated with managed care;
- the myriad operational changes necessary to provide services in a managed care environment;
- resources for engaging I/DD provider boards of directors about the changes associated with managed care;
- contracting with Managed Care Plans;
- the importance of data and financing arrangements;
- managed care laws, rules & regulations; and
- social determinants of health.

The MCCOP has launched a series of Regional Learning Collaboratives to facilitate discussions with I/DD providers, representatives from DOH and OPWDD and members of the MCCOP team regarding the managed care transition. We are pleased that the MCCOP is also focusing resources to provide opportunities for individuals with I/DD, parents and family members to learn more about managed care with specific projects focused on:

- decision-making;
- knowing an individual's rights;
- grievance procedures;
- familiarizing managed care organizations with the I/DD population; and
- other specific technical assistance identified by self-advocates and families.

Currently, the MCCOP is focusing on the development of more training and technical assistance opportunities such as:

- **Higher level educational presentations** to help I/DD providers understand what they will need to do to prepare to enter into contracts with managed care organizations;
- **Focusing on Health Information Technology** (e.g. Information Technology Organizational Self-Assessment Tool development, implementation, analysis, and reporting; develop template RFP for providers to select EHR; conduct EHR vendor fairs);
- **Reporting & Financial Modeling** (e.g. convene tool development workgroup, develop metrics, develop tool; conduct in-person/web-based training on use of tools; convene



report standardization workgroup; deliver Medicaid claims based benchmark and profile reports for individual providers; conduct web-based/in-person (as necessary) training on benchmark and profile reports);

- **Publishing a White Paper** highlighting particular aspects of 5 states' approaches to managed care for its I/DD population, and what can be learned for New York State; and
- **Establishing a Managed Care Resource Center for People with Disabilities and Families.**

We remain excited at the opportunities ahead of us to provide more technical assistance and training to all stakeholders. Much of what the MCCOP has accomplished to date can be accessed by going to the MCCOP website at www.mc-cop.com

The NY Alliance thanks the Governor for including ongoing investments in the Executive Budget to support the work of the MCCOP and respectfully requests the support of the State Legislature to fund this important and necessary training and technical assistance program.

Specialized Intellectual/Developmental Disabilities Ombudsman Program

The NY Alliance strongly believes that the role of an Ombudsman is essential in publicly funded human services delivery systems and is especially vital when new systems are put in place.

An ombudsman is officially charged with representing the interests of the public and is independent from government. A (NYS) Substance Use Disorder and Mental Health Ombudsman was recently created, rightfully so, which helps individuals and their families navigate New York's behavioral health care system to ensure people have access to necessary care and services and also to help resolve issues when care has been delayed or denied as part of the newly created Health and Recovery Plans (HARP) within DOH.

The I/DD sector will soon implement managed care and such a role specific to the population currently does not exist. Given the complex needs of people with I/DD and the challenges they oftentimes face understanding changes to their services and benefits and the complicated language generally associated with Medicaid underscores the necessity for a specialized ombudsman program. We therefore call upon the Legislature to include \$1 million in funding to establish a specialized I/DD Managed Care Ombudsman.

The specialized Ombudsman would be tasked with assisting people in New York's I/DD system and their families to navigate the new managed care environment, which includes but is not limited to:



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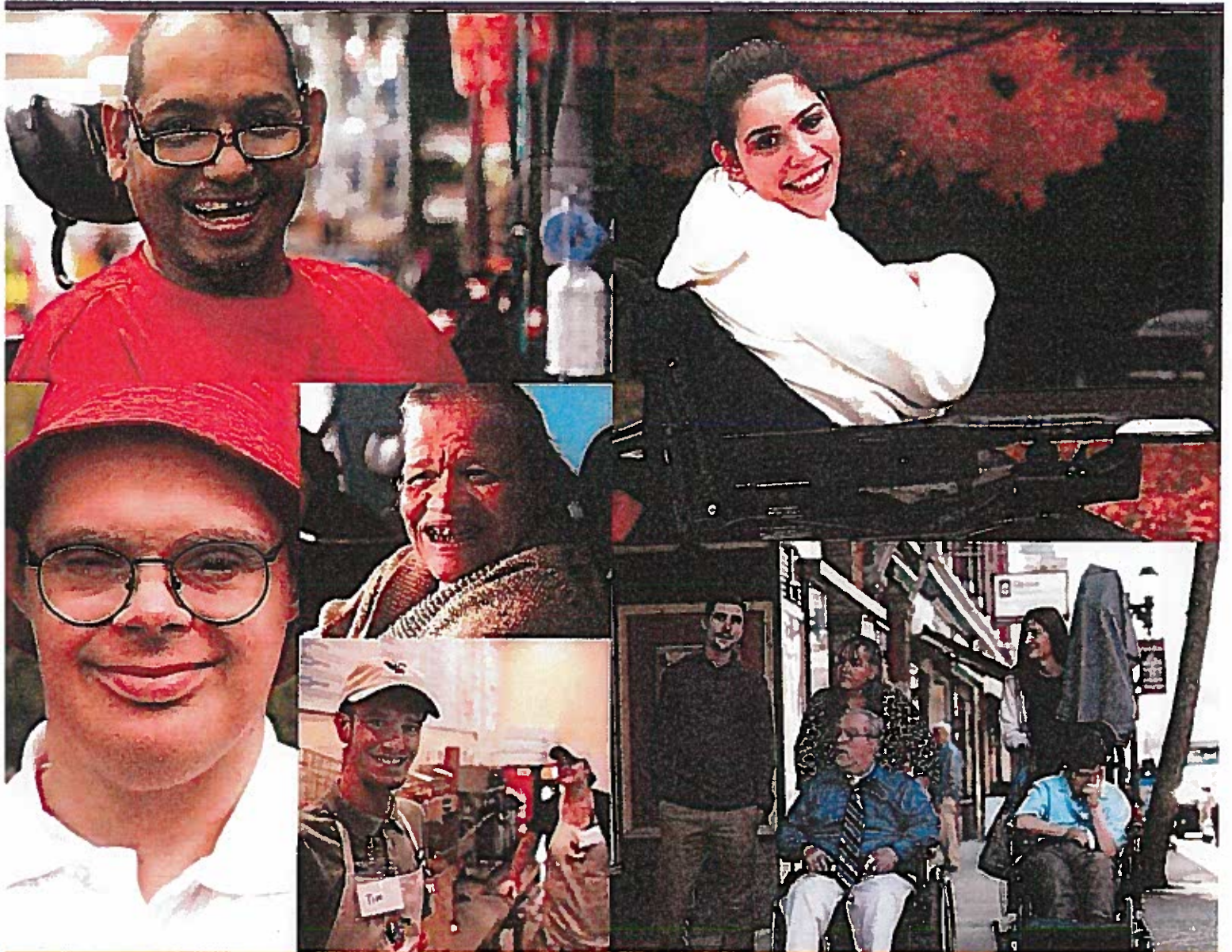
- denials;
- complaints and grievances;
- quality monitoring; and
- health outcomes measures and display metrics on specialized, I/DD provider-led managed care plans and other managed care entities.

Closing

On behalf of the NY Alliance, we thank you for the opportunity to provide you with our recommendations and feedback on the 2020-21 Executive Budget.



Office for People With Developmental Disabilities



Raising expectations, Changing lives



OPWDD: Putting People First

Dear Reader,

When I invited people to join the Transformation Panel in February of 2015, one thing seemed clear to us all: this is a moment of opportunity for people with developmental disabilities. We have a chance to shape more individually tailored services for each person and a more sustainable system for all. The recommendations from this group, in the state that has been a leader in supporting people with developmental disabilities for decades, can be simply summarized: go further.

As I have spoken with many people served by our system and heard how worried and uncertain people felt about the future, I thought it was very important to open up the process of change. I invited people with different perspectives, from self-advocates to parents of children with developmental disabilities, people from the provider community and expert advisers to help define ambitious goals and innovative ways of attaining them. In this process, one thing has become very clear to me: we are in this together.

The Panel members identified the challenges we need to address and the opportunities we can seize on to help people with developmental disabilities live the fullest lives possible, helping them thrive in the community, as citizens, neighbors and friends. This diverse group has worked through 2015 to help reimagine and redesign systems of support.

I felt it was important for this Panel to represent different perspectives and, as expected, there are varied opinions about many of the specifics in the report and recommendations that follow. Being open to these different viewpoints is an important part of making real progress.



OPWDD: Putting People First

In September, members of the Panel joined me in listening sessions around the state that were extremely important as many people took the opportunity to help shape this process. The one priority that really stood out is that people with developmental disabilities and those who care about them want to be assured that needed supports will be available in the future. They want to know that our systems of care will be secure and sustainable for years and decades to come.

New York State has been a leader in the care of people with developmental disabilities. To continue that leadership, it is important that we ambitiously pursue opportunities for people with developmental disabilities to live and work in the community. We want to fully support both those individuals who benefit from the expertise of provider agencies, and those individuals who prefer to shape and administer their own support plans via self-direction.

There are many different perspectives and opinions on the subject of supports for people with developmental disabilities, but we can all agree on two basic realities: first, our current system of supports needs to evolve to reflect changing needs and a different regulatory environment; second, that the process of discussing, designing and implementing change should be open to us all, including people receiving services, their families and caregivers, as well as provider agencies and policymakers.

I convened the Transformation Panel early last year to help ensure that the process would be as open as possible at every stage. The listening sessions held in September reminded us that change must be carefully managed and thoughtfully communicated, and also made it clear that many welcome the opportunity to be heard and to participate in the discussion.

An important message we heard in these forums and the



OPWDD: Putting People First

development of recommendations by the Panel is that while ensuring that supports will be available in the future is a priority for families and providers, there are present needs that also must be met. The need to address today's issues while planning for tomorrow is not unique to our field or to this particular process of change. One of the most important immediate concerns is addressing the needs of individuals living at home. To respond to those needs, OPWDD will dedicate a significant amount of new funding in the 2016-17 Executive Budget to support those now living at home, including making residential opportunities more available when living at home is no longer the most suitable option.

The need to provide appropriate residential opportunities to individuals with developmental disabilities is one of the most important issues the Transformation Panel considered. A report to the Legislature that is also being released describes the outreach OPWDD made to 11,000 individuals reflected on the Residential Request List who had at some time in their history with OPWDD indicated interest in residential supports. One of the recommendations of the Transformation Panel is that OPWDD develop a five-year comprehensive housing plan to address the need for safe, accessible, affordable and individualized housing supports for people with developmental disabilities. As with the implementation of other recommendations of the Transformation Panel, OPWDD will continue to work with individuals, families, advocates, and providers, to develop effective solutions to meet the needs of people with developmental disabilities.

The people who have contributed their time so generously to this Panel are, like the staff of OPWDD, inspired by the efforts that those with developmental disabilities and caregivers make each and every day. These recommendations are designed to honor them by helping to inform and accelerate the development of the



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responsive supports they need and deserve.

These recommendations will form the basis for a detailed implementation plan that will be completed in the coming months. Panel members will be asked to meet regularly to review our progress in meeting the objectives of the implementation plan and we will regularly report our progress to you as well.

I thank you for your participation in this process.

Sincerely,

Kerry A. Delaney

Acting Commissioner

Office for People With Developmental Disabilities



Introduction: The Imperative to Transform

Today the entire healthcare system in our country is being reconceived to meet the needs of the future. The OPWDD system is also evolving, for two simple reasons: more people require supports and the needs of the people we serve are changing. Not only are more people entering our system, many are requiring support for a longer time. In addition, integration in the community has become a realistic goal for many individuals and new practices make it possible for supports to be tailored to meet each individual's unique needs.

At the same time, government and providers need to adapt and innovate together as the focus shifts from what services are delivered to the results and outcomes achieved. This change will affect regulatory and oversight requirements along with how supports are paid for, designed and delivered.

Three simple strategies make the process of change easier for all:

- Building on the successes of the current system in helping individuals participate in the community whenever possible;
- Offering support for the family members and the direct support professionals who are the foundation of our systems of care; and
- Involving individuals and families in planning for these changes.

Some individuals with developmental disabilities need 24-hour assistance in residential and day supports and, of

The OPWDD system is evolving, for two simple reasons: more people require supports and the needs of the people we serve are changing.



course, when people with developmental disabilities grow into old age, they confront new and different challenges.

Recognizing that more independence is possible for many demands us to aim high, evolving tailored supports to meet the needs of those who want to live and work in the community, volunteering and engaging in the ways that matter to them. If individualized supports are the goal, we need to acknowledge that our current system lacks that kind of flexibility.

Changing complex systems is never easy or fast, but in managed care and value based payments we have models based on the simple idea that rewarding good outcomes and containing costs in a measurably effective system works for all if we can preserve the essence of the OPWDD service delivery system.

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The Changes Underway

Over the last several years, OPWDD has focused on helping more people find jobs, live in the community and direct their own services. To do this, the agency has helped people explore the kinds of work they want and created more ways for people to direct their own services.

The agency has worked hard to ensure that those who need support can get it and that no one will lose their services as a result of the transformation. Although we are still early in this process of transformation, we are encouraged by the initial measures of success.

- OPWDD has helped more than 650 people leave institutional settings and move safely to the community since 2013.
- There has been a three-fold increase in the number of people directing their own services: from 979 in June 2013, to 3,018 in September 2015.
- As of the end of July 2015, 7,823 individuals are competitively employed and making at least minimum wage in an integrated setting. Additionally, 12,687 individuals are receiving prevocational and other skills-based employment services such as the "Pathways to Employment" program.
- In 2014 and 2015, approximately 800 people per year who had been living at home were helped to find and move into a certified residential setting.
- OPWDD allocated a significant portion of federal Balancing Incentive Program funds to support transformation and stabilize providers and the service delivery system. OPWDD awarded over

Over the last several years, OPWDD has focused on helping more people find jobs, live in the community and direct their own services.



\$65 million in funds to 106 organizations to support initiatives designed to promote transformational outcomes including employment, self-direction, transition supports and community partnerships. OPWDD has also allocated approximately \$23 million to assist in the start-up of care coordinating organizations, and over \$40 million to assist providers in adapting to new rate methodologies.

We still have immediate challenges to face together. Rate transformation has put new pressures on providers and federal scrutiny has resulted in changes to how services can be funded. These developments are a source of worry for families, provider agencies and advocates, and that concern has added a sense of urgency to the Panel's work.

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Establishing priorities is all the more important because of the urgency of these concerns, and several immediate steps are underway to ensure that we can effectively meet the demands of today while we work to develop new service delivery mechanisms for the future.

- To help ensure that the many needs of those living at home with their families and seeking additional services can be met, a majority of the \$120 million of new funding proposed in Governor Andrew Cuomo's 2016-17 Executive Budget will be allocated to meet these needs.
- OPWDD will dedicate \$10 million of this new funding to serve the residential needs of individuals considered Priority Two or Three who are now living at home with a family caregiver. Local stakeholder groups will be established to work with



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Transformation Panel

OPWDD's regional offices to help guide the expenditure of these funds.

- OPWDD is undertaking an immediate review of the impact of rate transformation on our system, and will make recommendations for changes as needed to ensure the sustainability of our system.



The Panel Defines Key Priorities

The members of the Panel quickly agreed on a shared vision and the three categories that shaped the discussions around our future: community, outcomes, and flexible service delivery platforms.

Community: People with developmental disabilities will be accepted as part of our communities, living the lives they choose while experiencing good health, growth, and personal relationships.

Outcomes: The focus is on the quality of the person's experience and the outcomes the people we support have told us they want, which includes living and working in the community while directing their own services and supports.

Flexible Service Delivery Platforms: Integrated, quality services must be supported by networks of high performing providers with the flexibility to meet people's needs. All service delivery platforms, including managed care, should measurably further this vision.

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In addition, the Panel developed its *guiding principles* and framed a list of essential questions to ask of any new OPWDD initiatives, whether future program models or refinements of existing programs:

- *Does it help promote the integration of people and services in the community?*
- *Does it encourage the active involvement of people with disabilities and their families?*
- *Does it broaden the range of choices and options for individuals?*
- *Does it foster independence?*
- *Does it take those at the higher end of need into account?*
- *Does it use data to measure and evaluate quality and satisfaction?*
- *Is it clear and realistic in its language?*

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The Panel Identifies Key Questions

The Transformation Panel brought their very different perspectives to bear on a basic issue: identifying the essential issues to resolve.

- How can we expand housing options and help individuals become involved in the life of the community, with the support of the public?
- How can we help people find meaningful employment and volunteer opportunities, which address varied personal needs in the workplace and encourage others who play a critical role in helping them succeed on the job?
- How can we help people take control of their own services and their own lives, building supports that are responsive to individual goals, needs and potentials?
- How can we use Managed Care and Value-Based Payment models to increase the accountability and flexibility of the system by rewarding providers for good performance instead of paying the same fee regardless of the outcomes for the person while maintaining the essential nature of OPWDD's services?
- How can we create a system that will be financially viable for decades to come, and be modernized to provide more measurable and outcome-focused supports?

The Panel and its subcommittees shaped these recommendations while staying focused on overarching issues: the need to remove barriers and make operational details more clear; the importance of public outreach and education; and the accommodation of changing levels of needs is a key to individualized supports.

The Transformation Panel brought their very different perspectives to bear on a basic issue: identifying the essential issues to resolve.



Hearing from People Around the State

During September 2015, Panel members and OPWDD leaders heard from people receiving services, family members, and providers about the issues and barriers they face at a series of public forums. These comments, questions and ideas informed the Panel's recommendations, as well as OPWDD's Statewide Comprehensive Plan and Residential Request List initiative.

Forums were held in Long Island, New York City, Albany, Syracuse, Rochester and Buffalo. A videoconference was held to reach Plattsburgh, Binghamton and the Hudson Valley. Hundreds of people attended the forums in person or sent in written testimony. All testimony received was provided to Transformation Panel members for their review.

*These comments,
questions and
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recommendations*



Shaping the Recommendations

The Panel's recommendations for transforming the system of supports for people with developmental disabilities will form the basis for the development of a more detailed implementation plan. The goal throughout has been to build upon the best of what exists in order to offer new opportunities and possibilities without ever compromising health and safety. Respect for the ideal of self-determination—the notion that we are all entitled to shape our own lives with those who care about us—has focused the entire process. Although terms like “managed care” and “value based payments” can sound impersonal, we believe these new service delivery models can address the need expressed most often by parents and other caregivers across the state—to be assured that their loved ones will be supported after they have gone.

OPWDD's goal is to provide more choice—in services, among providers, and in the way services are delivered. The idea is to help individuals realize their potential while removing the barriers in their path. The Panel's goal is to simplify the system, increase flexibility and put control in the hands of the individual whenever and wherever possible. There has also been consistent emphasis on ensuring that funding is available to enable transitions between levels of service as individuals' needs evolve over time.

The fact that these efforts can now be informed by data and enabled by the application of smart technologies is a reason for optimism as our field is challenged to find innovative ways to help people attain goals that once seemed unthinkable.

Respect for the ideal of self-determination—the notion that we are all entitled to shape our own lives with those who care about us—has focused the entire process.



Residential Support

The people who spoke at the listening sessions made it clear that the era of one-size-fits-all-models has passed—people want and need choices in how and where they live. Institutions were once the only option, but today the inclusion of people with developmental disabilities in the community is a real and achievable goal for many. What makes it practical is a multifaceted housing strategy that can meet the needs of someone who may need a lower level of ongoing support as well as someone requiring a traditional residential placement.

*The era of
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Detailed recommendations on residential supports can be found in the Appendix on page 20 of this report. As noted earlier, the report to the Legislature being delivered on the Residential Request List will play an important part in the development of an implementation plan for these recommendations.

Employment and Life in the Community

In the Panel's discussions and in comments made at the September forums, one point was repeated frequently: while we all support the ideal of inclusion, and all agree that making friends, having a job and feeling accepted are things we all want for ourselves, it is not always easy to help people with developmental disabilities get there. There are many challenges and no quick fixes, but as we move away from a focus on group settings there is plenty of room for new approaches that promote real and meaningful involvement in community life.

Detailed recommendations on employment and community



life can be found in the Appendix on page 21 of this report.

Self-Determination

Our systems of support need to move away from a regimented approach in order to make choice a reality. Supporting self-determination simply means assisting people in making their own choices. Each of us, whether or not we live with developmental challenges, wants some control over our lives. Making self-direction available, even though it will not be the right option for everyone, is a big step toward offering many people with developmental disabilities greater control of their own supports and services.

Detailed recommendations to promote both self-determination and self-direction in our system can be found in the Appendix on pages 21-22 of this report.

Supporting Staff and Family Caregivers

People with developmental disabilities are supported by family and friends as well as paid caregivers, and these family and friends deserve and need to be supported in turn. This may take the form of a short term respite or better community based supports, but one way or another such dedicated people need to know that they are not alone and can rely on OPWDD's guidance, expertise and advocacy. Careful consideration needs to be given to ensure resources are available to families who are caring for their loved ones at home, and steps taken to address immediate needs as well as plan for long-term residential support.

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Detailed recommendations on strategies to support caregivers and staff can be found in the Appendix on pages 22-23 of this report.

Service Delivery Platforms

We need modern, responsive and effective payment platforms to meet the varied demands of individuals and families. Our current system was built for a different time and we now need more streamlined and cost-effective alternatives. We now have the ability to use data to measure the effectiveness of what we do while improving the way services are coordinated. By focusing on what works—by measuring outcomes and rewarding providers who achieve good results for people— payment platforms like value based payments, if they are carefully designed to preserve the unique nature of OPWDD's services, can work for everyone.

Detailed recommendations regarding system platforms, including topics such as funding and regulation, can be found in the Appendix on pages 23-24 of this report.

Implementing the Recommendations

The success of the Transformation Panel's recommendations rests on the ability to implement them in a timely and transparent manner. An implementation plan is being developed by OPWDD with Panel review to put the recommendations into action. The implementation plan will be completed in the coming months, and progress on reaching implementation goals will be tracked and regularly reported on to you. Panel members will be asked to come together on a monthly basis to review progress toward the implementation plan objectives.

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Conclusion

New York State has been a leader in supporting people with developmental disabilities and this Panel has been inspired by the sense that today we have the opportunity and the obligation to go further to meet the needs of people with developmental disabilities. These recommendations are the result of connecting bold ideals to practical realities. There is no pre-existing blueprint for this work and no ready-made answers to the many questions asked of the Panel during the listening sessions. What is clear is that, if we work together, we can support many more people with developmental disabilities in the community and the workplace with a wider range of options available for all.

The journey to acceptance is not rapid or easy, but that has not stood in the way of New York State as it has pioneered the rights of people with disabilities in the past. The Panel's work is not over, but in identifying the key issues to address in shaping a modern and sustainable system it has performed an invaluable service. First and last, this diverse group reminds us of a simple fact of life: we are all in this together.

We all have the right to a rewarding life lived on our own terms, despite challenges and difficulties. People with developmental disabilities deserve to know that their fellow citizens and government are working together to create accountable and transparent systems of care and shape a new era even more groundbreaking than these last, extraordinary decades in New York State. It needs to be said, in conclusion, that this work is a new beginning: the road to a system that supports people with disabilities as fully participating citizens of our communities starts here.

The road to a system that supports people with disabilities as fully participating citizens of our communities starts here.



Appendix: Detailed Recommendations

Residential Support

1. Make new funding available dedicated to those living at home. A majority of the \$120 million in new funds proposed for OPWDD's budget for 2016-2017 will be allocated to meet the needs of those living at home, including those on the Residential Request List. A total of \$10 million of this funding will be allocated to OPWDD's Regional Offices to meet the needs of individuals identified as Priority Two or Three. The \$10 million allocated to the Regional Offices will be administered with input from local groups of individuals and families.
2. Initiate a review of certified and non-certified housing inventory in each OPWDD region in order to identify needs and evaluate resources for each region. This review will include an analysis of shared living options, affordable housing, home of your own and other models in order to ascertain the complete picture of available housing and best inform decision-making. This work will be informed by the stakeholder groups established in recommendation 1.
3. Ensure that individuals living at home and those living in institutional settings have access to residential services based on need. Continue the current trend of providing more than half of available certified residential opportunities to those living at home and focus on providing requested in-home support to ensure that family caregivers are supported with a wide spectrum of supports to meet their needs as well as residential opportunities when needed.
4. Evaluate the prioritization of access to residential services to ensure that those now at home are treated fairly by reviewing the prioritization criteria which drive the allocation of residential services, particularly focused on ensuring access for those with more significant needs.
5. Help people understand their residential options and learn about the choices they may have by using a person-centered planning process to identify individuals interested in moving from a setting with 24-hour supervision to a residential setting offering less oversight and more independence.
6. Develop a Five Year Plan for meeting the housing needs of those living in or seeking residential services. The plan will be informed by the Residential Request List (RRL), the survey identifying those interested in moving to a more integrated setting, and the certified and non-certified housing inventory.
7. The Residential Request List survey results should be updated frequently to assist in long-term planning and gauging changing demand over time.
8. Ensure that individuals with developmental disabilities are a key constituency in statewide affordable and supportive housing initiatives by allocating \$15 million in capital funds proposed for OPWDD in the 2016-17 Executive Budget to fund the development of supportive apartments.
9. Establish a system of housing support that is flexible, so that the level of support a person gets can be easily increased or decreased as their needs change by increasing or reducing the amount of in-home support a person receives and/or supporting the individual in another service setting on a temporary basis.
10. Work with Intermediate Care Facility residents and providers to ensure meaningful opportunities for home and community-based services by ensuring a smooth transition to other residential options or in conversion to other types of facilities.
11. Engage in comprehensive outreach about available housing so individuals and their families understand how to access community housing options.
12. Engage in comprehensive community outreach to help the public better understand what developmental disability is, and be welcoming of people with developmental disabilities in the community.



Appendix: Detailed Recommendations

Employment & Life in the Community

1. Develop a flexible day service model with simplified reimbursement mechanisms to allow individuals to seamlessly transition between employment, pre-vocational services and day habilitation while giving families the security of a full-time schedule. The model should allow people to “mix and match” their activities during the day—including employment supports, day supports and community activities—to arrange a full-time schedule, personalized to meet the individual’s interests and needs.
2. Ensure continuity of work opportunities for those in sheltered workshops by providing technical assistance to workshop providers as they transition to meet new CMS requirements and assist individuals working in the workshops to maintain or find new work opportunities. If the workshop chooses not to convert, provide meaningful work and day support alternatives to those currently employed with the goal of ensuring that all those who want to be employed can be. Ensure these options are made available to those newly coming to the system, as well.
3. Conduct a multimedia campaign to encourage businesses to employ people with developmental disabilities by highlighting the contributions they can make to the workplace and the community. Share stories of success, as well as challenges people have experienced with regard to employment, volunteer work and community engagement.
4. Assist students in the transition from high school to employment through better coordination among state agencies, including the State Education Department, and schools. Start identifying skills and employment opportunities for high school graduates as early as middle school to help students with developmental disabilities think about their opportunities and the options that may be right for them.
5. Explore on-demand transportation as a means of providing flexible transportation around the community, and work to expand the availability of paratransit services and OPWDD’s partnership with the Department of Transportation.
6. Develop more volunteer opportunities to allow people to forge relationships in the community, meaningfully contribute, and provide a potential pathway to employment.
7. Develop retirement strategies for those who have reached advanced age and may not want to pursue employment or continue to participate in current day supports any longer. This will include connection to senior services in the community.
8. Set a percentage goal for the number of people with developmental disabilities employed by OPWDD.

Self-Determination

1. Ensure that funding is sufficient for individuals with greater needs to self-direct their services, maximize flexibility in how budgets are used, and ensure sufficient reimbursement for fiscal intermediaries (FIs) serving those with greater needs.
2. Simplify rules and requirements for self-direction. Publish reporting and documentation requirements in clear and understandable language for individuals and families, FIs, and provider agency staff.
3. Help individuals and families understand how self-direction works through a peer mentoring program and easy to understand communications materials. Conduct a comprehensive survey on self-direction in our system, including what is working and what needs improving. Through the survey, explore why some people choose to self-direct their services and supports and others do not.



Appendix: Detailed Recommendations

4. Develop strategies to infuse self-determination in all aspects of OPWDD service delivery by supporting people to understand their options and make choices in their lives whenever possible.
5. Develop strategies to better utilize community resources available to the general public, and encourage the use of such community assets in supporting people with developmental disabilities in a holistic way.
6. Foster relationships between people with developmental disabilities and their non-disabled peers through peer support and mentoring programs.

Supporting Staff

1. Conduct an overall review of compensation in our system, for direct support professionals (DSPs) and other staff, including reimbursement methodologies with a focus on supporting competitive compensation to ensure these staff can continue to be the backbone of our service delivery system. Recognizing the critical issues surrounding staffing in the OPWDD system, enhance focus on recruitment, retention, and the promotion of the field of developmental disabilities as an employer. Pursue strategies to reduce overtime usage and promote a good work-life balance for employees.
2. Implement the START crisis response model statewide as a strategy to ensure access to potent community-based crisis support, achieving statewide implementation in three years.
3. Implement a second phase of comprehensive training for Front Door staff to enhance the ability of staff to be responsive and develop effective service plans that meet the needs of individuals and families.
4. Develop next steps for implementation of a credentialing program and career ladders for DSPs so that there are clear opportunities for advancement and incentives for employee performance.
5. Incorporate the expertise of, and relationships of individuals with, Medicaid Service Coordinators in the redesign of service coordination for implementation through a care coordination model.

Supporting Family

1. Make new funding available dedicated to those living at home, as previously described. A majority of the \$120 million in new funds proposed for OPWDD's budget for 2016-2017 will be allocated to meet the needs of those living at home, including those on the Residential Request List. A total of \$10 million of this funding will be allocated to OPWDD's Regional Offices to meet the residential needs of individuals identified as Priority Two or Three. The \$10 million allocated to the Regional Offices will be administered with input from local groups of individuals and families.
2. Explore creative models for supporting caregivers, including the pooling of resources among families who want to work cooperatively to meet the mutual needs of their families.
3. Finalize review of respite needs in communities throughout the State in order to develop regional plans to increase options where a need for additional respite services is determined.
4. Engage in a yearly outreach to those on the RRL to help better plan services for people now living at home, and ensure we are meeting emergent needs. Ensure that individuals who have been cared for by family members at home receive at least equal priority for more extensive services when they are needed



Appendix: Detailed Recommendations

5. Develop a five year comprehensive plan to address long-term needs for housing, using RRL data.
6. Invest in targeted technologies to enhance the ability of families to get more assistance from natural and community supports
7. Explore circumstances where paid family caregivers may be appropriate.
8. Ensure that caregivers are informed about pending changes in the system, such as new programs or modifications to existing ones, and clearly explain the potential impact on their loved ones.

Funding and Performance

1. Reevaluate resource needs to ensure adequate resources as transformational changes are implemented, to ensure resources are being maximized and targeted in alignment with implementation priorities.
2. Develop a "safety net guarantee" so that a person can try different things with the reassurance that their former level of services can still be there for them if they need to go back to their old service arrangement.
3. Build on recent efforts by the agency to increase transparency by posting a "dashboard" that indicates the number of services that are being provided to individuals by region on the OPWDD website.
4. Perform a review of the overall impact of rate transformation on providers to determine the impact on the sustainability of the system, including recommendations for amending rate methodologies where warranted.
5. Ensure that there is a fair and transparent regulatory process to eliminate retroactive rate changes and also ensure that there is sufficient time and clear guidance for providers to comply with changes.
6. Transition to a valued based payments system guided by stakeholders who help develop data driven quality measures. Develop and publish data metrics about system performance. These measures must be developed in conjunction with stakeholders, be appropriate to developmental disability and encourage and reward good outcomes. All savings generated from value based payments must be reinvested in the OPWDD system.
7. Ensure accountability by providing online access to information, pricing, and services via portals and individual accounts.

Flexibility and Responsiveness

1. Provide options and funding appropriate for those at the higher end of need, including those with a dual diagnosis, to support those with complex physical, medical or mental health needs.
2. Review regulations for opportunities to streamline the system, to allow for flexibility and innovation.
3. Support a predictable regulatory environment through sufficient notice of changes to providers and elimination of retroactive rate setting.



Appendix: Detailed Recommendations

4. Implement HCBS settings regulations in a way that ensures person-centered planning for individuals and maximizes integration and choice by focusing on the spirit and intent of the regulations and collaboratively assisting providers to comply. Offer technical assistance to providers concerned with the potential impact.
5. Create a feedback loop with each change to document success in the system and identify areas for improvement.

Care Management and Assessment

1. Reinvest savings achieved through managed care in the OPWDD system to enhance existing services and support more people.
2. Identify funding to meet the administrative costs of managed care, distinct from funding required to meet the needs of individuals for services.
3. Consider initially not including certified residential services in the funds paid to managed care entities, and instead focus care management on community supports and services (wraparound supports) initially.
4. Review the impact of incorporating healthcare services in care management from the outset as a means of providing holistic care to the individual.
5. Evaluate care management on a regular basis as it is implemented to ensure it is meeting desired objectives for those served through the OPWDD system, and allow time to evaluate the managed care design model before mandatory enrollment begins.
6. Ensure that OPWDD services are coordinated by experienced entities with expertise in providing services to people with developmental disabilities.
7. Ensure that individuals who are not happy in managed care can return to their current arrangement during voluntary enrollment.
8. Advocate transitioning OPWDD services to managed care using an 1115 waiver to allow for maximum flexibility.
9. Implement the new Coordinated Assessment System (CAS) assessment tool and needs analysis as soon as possible to ensure fair and equitable treatment of all individuals and families in determining service needs.
10. Ensure that the input of families and individuals guides any service changes considered, and that reliable assessment data is used when evaluating options.

Transformation Panel

Convened by Kerry A. Delaney, Acting Commissioner
New York State Office for People With Developmental Disabilities (OPWDD)

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