



***KEEPING THE PROMISE ALIVE:  
ENSURING A SUCCESSFUL TRANSITION TO  
MANAGED CARE***

*A Position Paper by  
The InterAgency Council of  
Developmental Disabilities Agencies, Inc.  
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## ***Keeping the Promise Alive***

### **BACKGROUND**

For persons living with intellectual and developmental disabilities (I/DD) it is a new day and a new era. New York already has one of the most comprehensive arrays of service options in the nation, which includes a mature and extensive system of certified day programs and 24-hour supervised residential programs developed over the past 30 years. As a result of New York's decades-long innovation and commitment to build its unique system, families and individuals (along with OPWDD encouragement) have come to look forward to their move into a community-based group home as a rite-of passage. This is similar to the way typically developed brothers and sisters look forward to their own moves out of their parental home to independent "adulthood." All citizens of New York State should feel proud of these significant accomplishments. However, for better or worse, the delivery of supports to individuals with I/DD is changing, and changing rapidly.

Current circumstances are driving a paradigm shift away from 24-hour supervised residences to in-home services and supports and from traditional full day habilitation services to partial day services and employment opportunities; from provider directed care plans to self-directed care. While the CMS /OPWDD Transformation Agreement offers expanded employment, self-direction options, community service opportunities and independent living options, the scope and speed of this effort presents NYS with a major challenge to deliver on these promises. What is required is a network of high quality person-centered services that meet individualized needs (including those individuals who require more intensive supports) with a full range of service options, without destabilizing the existing system of services. The new Front Door process, in combination with the move to a managed care framework to execute the transformation agenda, adds layers of complexity and ambiguity for both the design and implementation. It is not surprising that the speed and breath of the proposed changes create an environment where individuals and families are concerned about the future of the system that has been designed to meet their unique needs. Service providers share those significant concerns.

In 1998, the state initiated the New York State Cares program. This was an historic initiative that promised to allocate sufficient funds to address the residential needs of adults with I/DD seeking their own residential experience, but who were still living at home with their families. That promise today, is actively alive in both individuals' and families' minds. Today's overarching goal must be an assurance to keep that promise alive while seeking to offer a new path that will offer an array of person-centered, flexible, high-quality services and supports that meet the needs of individuals with I/DD and their families.

Toward that end, the Interagency Council of Developmental Disabilities Agencies, Inc. (IAC) offers this Position Paper to provide recommendations to guide the development and execution of OPWDD's Transformation Agenda and the development and execution of managed care for people with I/DD. The People First Waiver proposes OPWDD's most significant overhaul in 35 years and, as a result, we share a tremendous collective responsibility to ensure it is operationalized correctly from its beginning. Anything less must be considered unacceptable.

## ***IAC's VISION***

Regardless of the extent of their disability, people with I/DD and their families will be supported in such a manner that allows them to achieve personal dreams and goals so that they can live, play, be educated and employed within the communities of their choosing. IAC envisions a person centered system whereby individuals with I/DD and their families are able to choose the right amount of supports and services from among a comprehensive array of options to enable fully integrated lives in the community of their choice.

## ***GUIDING PRINCIPLES***

- There must be an inherent commitment by New York State that ensures individuals receive supports and services that foster their continued growth and independence to the best of each individual's capability.
- There should be access to employment and/or other meaningful activities with the sufficient level of supports to meet each individual's need for as many days each week as necessary to achieve their desired outcomes.
- The unique value of each person served must be recognized, and they must be treated with dignity and respect.
- Choices that allow individuals with I/DD to entertain new and different options at various stages of their lives need to be made available. Individuals and families should be able to navigate easily among the array of various choices open to them.
- People with I/DD who want to self-direct their supports should be able to do so with clear guidance and with minimal obstacles, including the ability to modify the level of support they receive as their needs change.

## ***THE OPWDD TRANSFORMATION AGENDA AND ITS CHALLENGES***

The system supporting people with I/DD and their families in New York has been undergoing massive reform during the last five years. Multiple and sometimes conflicting factors are at play. New York State is responding to a series of new transformative expectations from CMS; grappling with the implications of the Olmsted decision and displaying the consequences of multiple personnel changes within the OPWDD hierarchy, while at the same time implementing a statewide transition to a managed care environment for both long-term supports and acute healthcare services. While OPWDD has created a highly transparent process involving many stakeholders, the myriad of changes proposed are so significant and far reaching, that individuals and families appear to be struggling to understand the cumulative impact of these changes to their specific circumstances. Those of us in a position to assist (OPWDD, community agencies, advocates) need to step up and assist individuals and families to proactively navigate the new system.

OPWDD is shifting its approach to residential supports away from certified residential and day facilities to more home-based and integrated individualized supports. For individuals with 24-hour support

needs, this public policy shift has resulted in their families feeling “left out” of OPWDD’s planning. They know what will NOT be available for them, but are not clear what services will be available to meet their needs, including the extent of those services, and how to access them. In addition, OPWDD’s new Front Door intake process has resulted in significant delays in the commencement of services.

Another relevant factor is the US Department of Justice’s pressure on states to implement Employment First principles which assumes everyone can and wants to work. This has required New York to restrict admissions to sheltered work settings and to develop a plan to eventually close them. It will also mean that day habilitation programs will no longer be the automatic service of choice--particularly if they do not offer significant opportunities for regularly scheduled activities in truly integrated environments. Families will need to understand what these changes mean for individuals who receive supports from OPWDD. While Employment First is clearly the priority, families who currently rely upon OPWDD supports to provide meaningful daytime activities to their family member will face new challenges if the employment opportunity is less than full time Monday to Friday. Certainly, while some individuals with I/DD will obtain full time employment, many others will obtain part time employment for a few hours a day or a couple days a week, leaving vast stretches of time that will need to be filled with other meaningful activities. While competitive employment may be the ultimate goal for many individuals, valuable meaningful activities must also be accessible and reimbursable to ensure all individuals served lead full and rich lives. For those who will still choose day habilitation services as their primary form of day support, agencies will need to re-envision those services to ensure they are provided in the most integrated community-based environments possible.

### ***Recommendations***

1. OPWDD must establish a comprehensive system of identifying unmet needs and create a plan for addressing them. This system must be comprehensive (paying special attention to those individuals requiring 24 hour supports who remain living at home with their families). OPWDD must ensure there are no fiscal disincentives to serving people with intensive needs. This plan should include:
  - Up to date data that indicates the number of individuals (by region) living at home with their families that are seeking residential, day and other supports.
  - A clear policy that describes how OPWDD envisions supporting people with complex needs who need 24 hour supports.
  - A comprehensive prescription for how OPWDD will communicate to individuals and their families the intended shift in culture from what people want and expect to one that will fund only what is assessed the individual really needs.
2. At minimum, the options available to families must include those comprehensive day-to-day support needs identified by National Association of State Directors of Developmental Disabilities Services (NASDDS) such as: Support Coordination, Personal Assistance, Employment Services, Community Guide/Facilitator, Benefits Counseling, Habilitation, Supportive Technologies, Home modifications, Cash subsidies, Long term planning, Respite care, Behavior intervention assistance and Crisis intervention services.

3. OPWDD, ACCES-VR, and the Department of Education (SED) must implement true transition planning in accordance with federal guidelines. In doing so, families' expectations can be modified to be more closely aligned with current realities. As a result, individuals should have enhanced opportunities to transition to work-readiness programs, and significantly more students will exit the school system prepared with many of the skills necessary to be successfully supported in a job in an integrated work environment.
4. OPWDD should invest funds into travel training curriculums and programs that will reduce individuals' reliance on agency-sponsored transportation systems towards the outcome of acquiring self-travel skills.
5. Supported employment (SEMP), supported living and consolidated support services (CSS) afford significantly more opportunities for activities in integrated environments than other HCBS services. Historically, their reimbursement rates have been inadequate to address the needs of individuals with intense and/or complex needs. Therefore these individuals are often relegated to more segregated environments. There must be flexibility built into these and other rate formulas that maximize integrated opportunities for all individuals.
6. Currently, many day habilitation programs offer highly enriching learning experiences in a broad variety of integrated community environment. Therefore, day habilitation must remain a support option available to individuals who are assessed to need such a service.
7. OPWDD should pilot a program that provides MSC services to students during their last two years of education to help facilitate their transition to employment and other OPWDD funded supports.
8. OPWDD should incorporate work-alternative options for individuals with I/DD to provide for a full day experience, regardless of the number of hours they may be employed. While the desired goal will be for most individuals to be competitively employed on a full-time basis in integrated settings, people must also have access to other meaningful supports when they are between jobs, work abbreviated hours, attend day habilitation or experience other factors that preclude full time employment.
9. The current OPWDD system is plagued with many examples of policies that are implemented in a highly inconsistent manner throughout the various regions of NYS. There must be procedural guidance documents that ensure uniform standards and consistent practices are followed in all geographic locations of the state.
10. Funding for Direct Support professional (DSP) wages should be adjusted as the minimum wage is adjusted and should include a guarantee of a reimbursement rate equal to or greater than 150 percent of minimum wage.
11. Workforce initiatives such as credentialing and apprenticeship programs should be continued and expanded to assure an abundant and ready workforce.

### ***TRANSITION TO MANAGED CARE***

It is widely acknowledged that New York has one of the largest and most comprehensive systems of HCBS supports in the nation, yet OPWDD is imminently poised to shift to a managed care framework. Significantly, there are virtually no models of other states that have transitioned a similarly complex statewide system of long-term I/DD services to a managed care model. While many states have

transitioned into managed care for their Medicaid population, the results are limited for persons with I/DD. As a result, the jury is still out regarding whether outcomes of long-term care services or overall quality of life for individuals with I/DD has actually been improved in any managed care environment. This paper is not designed to offer a profile of those states' experience but we are drawing from these experiences to inform IAC's thinking.<sup>1 2 3</sup> The feedback from our families in New York is that they are extremely apprehensive about the changes that will be brought by this transition. They are anxious that OPWDD funded supports will revert to the same medically based model that was previously deemed inappropriate and thus was discarded so many years ago. Individuals with I/DD and their families also believe there will be significant reductions to their services under a managed care environment. To better prepare for a successful transition, OPWDD and DOH have to directly confront these issues in an effort to alleviate the concerns of individuals with I/DD and their families.

A clearly outlined process must be articulated to reach a smooth transition to a managed care system. There is recognition that there will be many tension points throughout the transition to managed care. For instance, individuals with I/DD and their families will expect the same comprehensive array of services while under managed care, which is driven by cost-effectiveness; certain restrictions might be imposed on access to services and scope of benefits. Of additional concern to families is that managed care's constant attention to "medical necessity," will compromise OPWDD's historical commitment to guarantee life-long supports for individuals with I/DD. It is essential to validate managed care "per member per month" (PMPM) rates, particularly given the fact that an actuarially sound assessment with comprehensive data collection does not currently exist. Actuaries have the ability to project when data isn't available, and this is a crucial component under these circumstances. Required elements in a managed care system should include the capacity to collect real time data for incident reports as well as other issues impacting individual health, life and safety. This effort needs to also define the remaining data elements that will be required of the Managed care entity as well as those required of the provider networks. Representatives of each of these stakeholders groups should be a part of the dialogue on the data requirements.

The overwhelming lesson from other states is that current providers will need assistance to build capacity to report newly required data. Further, Managed care entities have never previously collected and/or reported data regarding long-term OPWDD funded services. Coding has not yet been developed for non-health related outcomes/behaviors and OPWDD must articulate a process to define all required data sets. Even if the state utilizes CQL's Personal Outcome Measures as the basis for developing its quality outcome measurement system, they must formulate the required metrics. Key outcome

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<sup>1</sup>See Critical Appraisal of the Topic: Managed Care in the IDD Field. Prepared by the ArthurWebbGroup, Ltd. 2013

<sup>ii</sup>In Kansas, A Fight Over Developmentally Disabled Shifting To Medicaid Managed Care JENNI BERGAL KAISER HEALTH NEWS DEC 05, 2013

<sup>iii</sup>Medicaid Managed Care for People with Intellectual Developmental Disabilities—Revisiting the Experiences of Arizona, Michigan, Vermont and Wisconsin. Dennis L. Kodner. ArthurWebbGroup, Ltd. May, 2012

measurements need to include employment; stable housing; ability to age in place; the presence of friends and robust socialization opportunities; individual satisfaction; along with the health and safety of the individual.

We believe that in order to provide more integrated care, control costs and provide families and individuals with broader choices in services, it is critical that the approach be implemented in a manner that builds upon the strengths of the current system of care. We do agree with OPWDD and DOH that better healthcare coordination should result in savings from reduced use of emergency rooms, that more creative use of community supports can yield fewer psychiatric and other in-hospital admissions, and that the not for profit service providers can provide higher quality care at lower cost and in less restrictive environments than state operations. We also agree that comprehensive care coordination could result in overall improved health care outcomes and that more flexibility in housing, habilitation and employment services could better meet individual's needs.

The People First Waiver is the most significantly important change in delivery of these services in the past 35 years and, as such, requires intensely careful examination. We applaud the commitment articulated in the People First Waiver documents to increase opportunities for self-direction, as well as the emphasis on ensuring individuals receive their supports in the most integrated and natural environments possible. One of the most significant changes anticipated is the inclusion of acute healthcare into an integrated managed care system within two years of the People First Waiver's implementation. We maintain considerable concern that the speed of this conversion (as currently envisioned) will be a significant challenge. Managed care entities have far greater experience with acute and primary health services than they have with long-term care services for individuals with I/DD. This is clearly an area of grave concern to IAC.

The People First Waiver will require an entirely new perspective regarding the provision and reimbursement of services. The establishment of managed care entities specifically designed for people with I/DD is clearly the most profoundly new concept in the People First Waiver. It also holds the promise of greater efficiency, improving quality and promoting the least restrictive setting. We also know that managed care for persons with I/DD is not a completely tested or proven concept. In furtherance of our common goals, we have identified several key features and issues that need clarity and explanation to achieve the shared state goal of "care management for all." As an overall consideration, we strongly support the state's efforts to encourage explicit relationships with experienced nonprofit providers for persons with I/DD. Using this approach, managed care entities will gain the benefit, expertise and relationships that nonprofit providers have with the people they serve.

Last year's Article VII legislation delineates a list of covered services that include OPWDD, DOH and OMH/OASAS related supports and services. A major advantage of the People First Waiver, as currently envisioned, is to allow for a seamless movement from one service to the other, regardless of which NYS department has oversight authority. While, we strongly support this flexibility, there needs to be increased clarity regarding whether these services actually become "entitlements" based upon the assessed needs of the individual. The anticipated scope of benefits of the People First Waiver is broad and robust covering all the services currently supported by OPWDD while also including services under

the state's managed long-term care plans and benefits for behavioral health. This set of benefits is comprehensive and will require having experienced providers in any and all networks. OPWDD's 2011-2012 Statewide Comprehensive Plan indicates that 20% of the individuals served by OPWDD funded services are under the age of 21, yet very little has been mentioned how children's supports will be impacted by a managed care approach. This series of significant issues must yet be addressed before New York State is prepared to responsibly move into a managed care approach to long-term supports for individuals with I/DD.

### ***Recommendations***

1. It is significant that even after two years of planning, NYS has not yet stated where the funds will be found to pay for the new infrastructure, care coordination and IT systems, and administrative expenses incurred by the new managed care system. Additional funds must be found from new appropriations above and beyond OPWDD's historical level of funding for service, thus avoiding a further drain on existing financial resources dedicated to services being provided.
2. Together, OPWDD and DOH should create a formal process that involves individuals with I/DD, their families, and providers, that will be charged with setting policies to address their stated concerns regarding transitioning from the current system to a successful managed care environment.
3. Managed care entities must be incentivized through both contract language and funding levels to support individuals with even the most complex needs.
4. Individuals who currently reside in OPWDD certified residences consider these facilities to be their "home". They and their families should receive a commitment from OPWDD and DOH that when transitioned to managed care, these individuals will be allowed to remain in their current residence as long as they desire.
5. OPWDD and DOH must commit that any fiscal savings generated by the new managed care environment (either from the OPWDD funded long-term supports or the acute healthcare sector) will be shared between the two in a manner that allows for more financial resources that will benefit OPWDD supports.
6. Prior to implementing managed care, OPWDD must identify the required data to be collected from providers as well as the managed care entities. In addition, an IT platform must be developed to facilitate cross communication among stakeholders (i.e. OPWDD, Managed care entities, provider agencies, etc.) before long-term supports are incorporated into a managed care approach.
7. Electronic Records and other Health Information Technology must be funded **prior** to OPWDD's move to managed care to ensure universality of a data collection system and the actual collection of data.
8. We request the State of New York establish a "meaningful use policy" that reimburses OPWDD providers for implementing (or having already implemented) a managed care ready electronic records platform that enables providers to capture, process and transmit the data necessary to meet the State's uniform reporting requirements for managed care services. The costs of the software and staff training for providers should be identified and new appropriations need to be



established in NYS's budget to prevent these costs (as well as related hardware and software expenses) being funded out of the current allocation for services.

### **INDIVIDUAL ASSESSMENT AND DOH RATE SETTING METHODOLOGY**

New York plans to adopt a new coordinated assessment system (CAS) for which an algorithm will be developed to allocate funds for services, yet it is unclear how this will be accomplished. It needs to include components that recognize the diversity of supports needed by each person including those with the most complex needs and should recognize geographic cost differentials within the state. A major concern that needs to be addressed is what happens in situations when the assessment performed (CAS) does not match the individuals' desired outcomes.

The assessment must also identify the stability of the current caregiver situation for each individual, if appropriate. AARP's Public Policy Institute issued a report in December 2013 regarding the need to include family caregivers when assessing needs in 1915 (c) HCBS waiver programs. Their results indicated only 15 states met AARP's criteria for having a family caregiver assessment. Their report recommended that family caregiver assessment should be a part of all assessment tools for Medicaid HCBS waiver programs and that assessment must include questions about the *caregivers'* own health and well-being, as well as any services or support they may need to be better prepared for their caregiving role. The report indicated New York was not one of the states that currently incorporate family caregiver assessments in their existing HCBS waiver process. According to AARP's report, a recent law in Rhode Island requires a family caregiver assessment if the plan of care for the Medicaid recipient involves a family caregiver, and that plan needs to take into account the needs of both the care recipient and the family caregiver.

### **Recommendations:**

1. Prior to implementing managed care, OPWDD must ensure the CAS system has been scientifically validated as an assessment tool as well as a tool for determining appropriate allocation of resources to meet each individual's identified needs.
2. New York's Actuary (Mercer) must publicly certify that the PMPM rates established by the New York State Department of Health underwrite the cost of the full array of covered long-term care (including non-OPWDD funded) benefit services based upon a comprehensive assessment of the prospective need of the individuals with I/DD who will enroll in managed care.
3. The new PMPM rates established cannot be based on previous utilization of services, which were routinely denied or never made available on a consistent and medically necessary basis. For example, many individuals have been routinely denied or unable to access personal care services although this will now be a covered long-term care benefit. Therefore any reliance of historical utilization is by definition fundamentally flawed.
4. The most critical component of operating a risk-based model is the level of reimbursement for the PMPM rates. OPWDD providers must be fully informed and involved in the actuarial analysis of proposed PMPM rates and receive sufficient information to clearly understand how DOH's newly developed rates for OPWDD certified programs will be applied.

5. We recommend a formal process be established that involves families, individuals with I/DD and providers to review how the proposed assessment tool will be used to direct resources that ensure the individual and their caregivers' needs are met.
6. Each service plan must also address the needs of the family caregiver raised during the assessment process to achieve a person- and family-centered service plan that best serves the individual with I/DD.
7. New York should consider instituting legislation similar to Rhode Island's regarding mandating family caregiver information being part of the assessment and resource allocation process.
8. Given the substantial property investments made by many providers, it is imperative that NYS policies be implemented that ensure the continued reimbursement of historically approved properties.

### ***SUMMARY***

We are truly at a historic time in New York's evolution of services to individuals with I/DD. No one should underestimate the enormity and complexity of the changes in OPWDD's service system at the current time. Implementing the agreed upon transformation agenda requires comprehensive planning and very careful implementation, and we are clearly still in the beginning stages of creating the requisite policies, procedures and infrastructure to accomplish these goals. Simultaneously initiating a new managed care model for acute and primary health as well as long-term care services presents challenges that can only be imagined. As a result, strong advocacy protections (including an ombudsman function) for people with I/DD must be in place as a requirement before Managed care entities begin enrollments.

Prior to going "live" with managed care, OPWDD needs to define the outcomes and metrics to be used to measure whether or not people with I/DD are getting the supports they need and those articulated in contract. Further, OPWDD must ensure both Managed care entities and providers have the IT infrastructure in place to collect the data necessary to measure outcomes. Any assessment tools must be validated for resource allocation and actuarially sound rates must be established. There must be flexibility to move from a rigid, process-burdened system to one where providers are funded for outcomes, not process; and, the funding necessary to start up the People First Waiver must come from a new pool of funds, not existing service dollars. OPWDD's move to a managed care framework should occur at a pace consistent with its ability to evaluate (in real time) the impacts of this transition, and allow for changes as deemed necessary. Only when it is apparent that all elements are ready to ensure a successful transition for individuals with I/DD and their families, should a statewide effort be initiated.

In closing, OPWDD has undertaken an extraordinarily complex set of tasks to simultaneously convert its long-term supports to a managed care system; transform existing services to meet new CMS requirements while addressing the unmet needs of individuals residing at home with their families. This paper is intended to offer real solutions to meet those challenges.