

# Value Based Payment Outcomes & Measures

1. Home: Outcome- Support individuals to live in the most integrated setting possible that can meet their needs.

Measures: Establish baseline of settings where individuals currently live

Assess change in settings in 1 year, 2 year and 3 year time frame for existing people; and

Assess settings of new persons in each year receiving residential supports as compared to baseline.

2. Meaningful Activities including work: Outcome- Support individuals to maximize their potential doing their choice of activities in the most integrated community based settings that can meet their needs.

Measures: Establish baseline of settings (where services occur) and activities (i.e. volunteering, employment, senior activities, etc.) that individuals are supported through various day services.

Assess change in settings and activities in 1 year, 2 year and 3 year time frame; and

Assess settings and activities of new persons in each year receiving day services as compared to baseline.

3. Health: Outcome- Individuals should have access to and be supported to have a healthy lifestyle.

Measures: Establish baseline of Chronic Health Care Bundle;

Establish baseline of Preventive Health and Dental Care (using a checklist); and

Establish baseline of Medication Regimen and Utilization.

Assess annually the changes in the chronic health care bundle, the preventive health and dental care and medication regimen and utilization.

## Value Based Payment Outcomes & Measures

4. Control of Supports and Services: Outcome- Individuals have the ability to control and make choices of their supports and services as much as they desire.

Measures: Establish baseline of HCBS settings checklist compliance; and  
Establish baseline of providing self-directed support/service opportunities (agency and individual directed).

Assess annually HCBS settings compliance and provision of self-directed support/service opportunities.

5. Access to Supports and Services: Outcome- Individuals are able to get access to the supports and services in accordance with their life plan all within a reasonable timeframe (i.e. 30-60 days).

Measures: Establish reasonable benchmarks for individuals gaining both access to their supports and services and timeframes for receipt of those supports and services.

Assess annually the comparison of agency performance to benchmarks.

6. CQL and/or NCI survey performance: Outcome- Agency is CQL certified and/or completes NCI data metrics annually to examine overall agency performance.

Measures: Establish baseline of CQL (POM's) and/or NCI survey performance.

Assess annual agency improvement of overall performance compared to both itself and, after a period of time, to other agencies.

## Comment on New York State Department of Health "Value Based Payment Arrangements for Adults with Intellectual or Developmental Disabilities"

The Centers of Excellence in the care and treatment of children with autism spectrum disorders and other complex disabilities offer the following comments/suggestions in response to the DOH paper on value based payment arrangements for adults with intellectual or developmental disabilities. While part of the work done by the Centers of Excellence has focused on the development of measures for children, each of the Centers has experience in providing supports for adults with developmental and other significant disabilities.

Given the stated goals of Value Based Payments (VBP), being to “reduc[e] avoidable hospital use by 25 percent, and improv[e] the financial sustainability of New York State’s safety net,” it’s important to note the intersection of providers and supports and services will play in effectively contributing to New York’s success in meeting that goal. Many of the people we support are high users of health services and it will only be through improved integration with other components of the health delivery system that the objectives of the VBP initiative will be met. Moreover, the various processes and outcomes measures that are discussed in the DOH paper raise some concerns due to the lack of integration (acknowledged in the report by CAG members) in health system networks by the disability service provider community. This is a critical point that must be recognized as disabilities providers move forward at a different pace across the State implementing care management activities and care coordination with other providers in the health delivery system.

Another broad comment is that the value based outcomes must incorporate metrics that truly align with the outcome identified. Once the metrics are identified, they must continuously be re-evaluated for their appropriateness and alignment with the outcome – we can’t assume that the metrics initially identified will in fact demonstrate the “value” they were expected to assess. While value-based payment arrangements offer the opportunity to better align the interests of patients, providers, and payers, it is important that they be designed in such a way so as to avoid unintended consequences. Agencies that provide services to individuals with disabilities often have small patient panels, making it difficult to determine whether poor performance on outcome measures reflects poor quality, unreasonable expectations or simply bad luck. Because individuals with complex medical and / or behavioral conditions vary so much in terms of their physical and mental functioning, incentive arrangements that do not account for differences in patient characteristics between agencies will discourage agencies from treating those individuals who are anticipated to cost more. This is why we believe a reliable acuity measure must be further proven and developed before many of the outcome measures are used to compare “value” – we believe many of the process measures will lend themselves more quickly to such use, but caution on implementing incentives based on outcomes that truly do not reflect acuity differences across providers.

Additionally, VBP measures must be provider-centered, rather than patient-centered, because they are designed to incentivize providers to take active steps to better manage care and

reduce cost. Use of "process of care" measures versus "quality outcome" measures can reduce, but does not necessarily eliminate the problems. For example, measuring BMI is a process measure, which will capture whether the provider is measuring this metric. However, stating that the individual served should be within normal limits for a BMI measure provides for an outcome that conceptually should improve the individual's health outcome. Providers may find it easier to achieve process of care standards for patients that have higher levels of functioning, for patients in the community, and families with more resources, but there is no guarantee that health costs will be lower or that the individual will be healthier.

Outcome measures, such as many of the POMs, do not take into account unreasonable expectations of patients or their families, or cognitive limitations that impair the ability of the patient to make rational choices or evaluate wants and needs on an informed basis. Because of this inherent variability, the POMs process measures need to be commensurate with the individuals' functioning level. In general, we do not support the use of POMs measure in any way other than from a process perspective – is POM's being implanted, to what degree do staff use POMs in supporting people, etc. The "outcomes" in POMs are too subjective and will be almost impossible to quantify in any statistically reliable way for VBP measures.

We also encourage the identification and development of safeguards to be built into the VBP system to protect providers from being penalized or rewarded unfairly. For example, performance measures in Medicare's Nursing Home Value Based Purchasing Demonstration were risk-adjusted to reflect patient acuity/complexity, which is routinely reported in the long-term care Minimum Data Set. Risk-sharing was one-sided, and performance was measured by comparing outcomes between participating facilities and non-participating facilities with similar characteristics. We understand the use of corridors will accomplish this to some degree, but ask that ongoing review of impacts on providers be part of the development process.

Similarly, when measuring hospital quality, Medicare uses statistical methods that account for the fact that outcomes are more variable for facilities that treat smaller numbers of patients. The NYS Department of Health should consider to what degree these approaches can be adopted for value-based payment schemes for agencies that provide care for individuals with developmental disabilities, including those with Autism Spectrum Disorders (ASD) and related complex medical co-morbidities.

As has been noted in various presentations by DOH on this topic, decisions about calculating system cost prevention and details about member attribution will need to be determined before any reasonable decisions about VBP for the adult population can be made.

Finally, we provide suggestions previously submitted by CP of NYS regarding the specific measures and our recommendations for honing in on the outcomes identified in an appropriate and acceptable manner:

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6. CQL and/or NCI survey performance: Outcome- Agency is CQL certified and/or completes NCI data metrics annually to examine overall agency performance.

Measures: Establish baseline of CQL (POM's) and/or NCI survey performance.

Assess annual agency improvement of overall performance compared to both itself and, after a period of time, to other agencies.



An Anthem Company

January 20, 2017

Acting Commissioner Kerry A. Delaney  
Office for People With Developmental Disabilities  
44 Holland Avenue  
Albany, New York 12229

Dear Acting Commissioner Delaney,

Empire BlueCross BlueShield HealthPlus (Empire) is pleased to provide comments on New York State Department of Health's (NYSDOH) *Value Based Payment Arrangements for Adults with Intellectual or Developmental Disabilities (IDD): Progress Report of the IDD Value Based Payment Advisory Group* from December 2016.

As a partner to NYSDOH since 2005, we are one of the largest Medicaid managed care organizations (MCOs), currently serving more than 465,000 members in New York. Additionally, as part of the Anthem, Inc. family of companies, we bring together the best practices and experiences learned in New York with those of our affiliate health plans serving more than six million members in state-sponsored programs across 20 states and have a combined 25 years of experience.

Anthem is a leader in managing and coordinating health and support services to better meet the needs of individuals with intellectual or developmental disabilities (I/DD). We are the only managed care organization participating in all three risk-based state programs that fully integrate services and supports for individuals with intellectual and developmental disabilities (Kansas, Iowa, and Tennessee).

We strongly support employing innovative provider-payor collaborations to increase the quality, access, and cost-efficiency of services. As an organization, we recognize the transformative potential in value-based purchasing and have committed to substantially increasing the percentage of our medical expense spending tied to these programs across all lines of business. In fact, nearly 38% of our parent organization's 6.5 million members receive care from providers under an alternative payment arrangement.

We appreciate the New York State's Office for People With Developmental Disabilities' (OPWDD) efforts in engaging diverse stakeholders in systems transformation to support system redesign that is meaningful to all stakeholders (members served, communities, and providers) and that is sustainable for the State. Upon review of the State's report, we respectfully offer the following thoughts for OPWDD's consideration as the transformation of the delivery system moves forward.

#### **The Proposed I/DD Value-Based Payment Arrangement in NYS**

Empire is supportive of the NYS plan to incorporate beneficiaries with intellectual and developmental disabilities into the State's Delivery System Reform Incentive Program (DSRIP) and to move I/DD services towards Value-Based Payments (VBP). OPWDD's thoughtful and transparent approach, engagement with stakeholders in development of the plans, and incremental implementation is promising—especially given the complexity of the Medicaid-funded services and supports for this population, the variation among providers, and the need for development of foundational infrastructure (e.g.,

information technology and data systems) for VBP among many of the Home- and Community-Based Service (HCBS) providers.

Regarding the inclusion of members with I/DD, Empire believes it is important to incorporate people receiving long-term services in institutional settings, as well as those in home- and community-based settings—including self-directed services—in the VBP arrangements. By including members participating in the full range of services, the OPWDD will enhance the opportunity to ensure truly holistic, integrated services and improved care coordination for the maximum number of members. Including these members will also support further rebalancing of the system and improved outcomes as described in the goals of the OPWDD Transformation effort.

We strongly agree that establishing a *total cost of care* arrangement will serve members well. Far too often, members with I/DD experience challenges when the wide range of primary, acute, behavioral health, and long-term services and supports (LTSS) they receive are uncoordinated and fragmented.

We recognize that individuals with I/DD often experience a range of medical conditions that can adversely affect their health; further, these individuals more often have co-morbid physical health and behavioral health diagnoses. These factors, combined with the fact these individuals are often moving across different systems of care, can create challenges to accessing the appropriate care and services needed.

In the states where we serve members with I/DD, we utilize integrated screening and assessment processes, integrated care coordination, and a robust behavioral health provider network. We holistically identify and address members' behavioral health needs in tandem with their physical health and social support needs in a person-centered manner that honors choice and self-determination. We customize our approach based on member needs and the community organizations and/or waiver care coordinators with whom we partner. Support coordinators at our affiliate health plan in Kansas assisted more than 100 of our members with I/DD find employment, increase access to primary care services by 23%, and access to home and community-based services by 22%. The integrated system of care helped to achieve a better quality of life for members.

### **Member Attribution Logic**

While Empire agrees in principle with the suggested approach described in the report to attribute members to a provider group and managed care plan to create the VBP budget, we have questions about the intersection between this process with member choice and the provider's control of resources as described.

We agree that service providers and care coordination entities should absolutely benefit from the opportunity to achieve shared savings. However, as the OPWDD continues to consider methodology for member attribution, we recommend that member choice remain an important factor in this process and that nothing in the VBP arrangement inhibits or reduces the opportunity for members to select from a range of care coordinators/case managers and service providers. We agree with the State's assertion that the VBP arrangements must center around the member, and that the services and supports should be arrayed in response to the member's needs. This approach provides "maximum opportunity to respond to individual needs in flexible, creative ways" to achieve cost efficiencies and shared savings.



We also believe that a person-centered approach must remain central to the VBP implementation—and choice of providers is a critical aspect of operationalizing person-centered systems.

As the OPWDD considers options for the structure and requirements for the Care Coordination Organizations (CCOs), alignment with the goals for VBP as articulated in the progress report will be foundational to success of these reforms. We support the primary goal to “coordinate services across multiple service systems including medical, behavioral health, and long-term support services,” the focus on holistic and comprehensive care, and the acknowledgement of the need for enhanced information technology and data system capacities within the CCOs. Additionally, we believe careful consideration of the establishment of conflict-free case management structures and beneficiary protections, particularly related to choice, self-direction and self-determination, must be incorporated into the CCO design and reflected in the structure of the VBP arrangements for people with I/DD.

#### **Proposed Measures/Framework**

Empire applauds OPWDD’s decision to include a wide range of potential measures across multiple domains. Balancing quality measurement in a total care arrangement for people with I/DD is challenging, and the proposed NYS framework and measures is a good first step with the inclusion of both quality of life and clinical measures. There may be additional domains, such as caregiver support, which are important to the I/DD population that could be included, and several of the currently uncategorized measures requested by the Clinical Advisory Group (medication reconciliation, avoidable hospitalizations, care coordination quality, employment) should be included to assure a holistic set of measures.

We understand the current limitations in identifying and implementing defined and validated measures for quality of life outcomes, as well as outcomes specific to HCBS. However, we agree that using the selected Council on Quality and Leadership (CQL) Personal Outcome Measures® (POMs) can help define the quality of the services and supports and the individual outcomes of the participating beneficiaries.

We also appreciate the careful thought the Advisory Group put into categorizing measures, and considering a wide range of sources. We do respectfully respect clarification, though, on the categorization of the POMs measures. In the report, POMs measures are characterized as process measures. However, when implemented in a manner consistent with CQL standards, the resultant information provides outcome data. The structured interview questions that CQL designed for each of the measures lead to the determination that the outcome is either present or not present, and we are unclear why they have been characterized as process measures.

Implementing a system transformation such as this may be met with complications due to the several other initiatives or innovations providers and purchasers, such as MCOs, are currently making due to the federal home and community based service regulation, Department of Labor home care rule, and other requirements of the Affordable Care Act. To be successful with the VBP model proposed, it will be critical to involve stakeholders in each phase of implementation to create buy-in and commitment, and we appreciate the OPWDD’s efforts to do so throughout the process thus far. Also, we recommend that the OPWDD reassure stakeholders that strengths in the current system will be built upon—such as the use of POMs, NCQA, and CMS metrics which have national benchmarks established. When the final measures are adopted and the tools to gather the data are finalized, OPWDD can reassure stakeholders

that the metrics are fair, reasonable, and attainable as they are built upon POMS, NCQA, and CMS metrics which have established national benchmarks.

### **Balancing a Range of Measures**

Empire believes that an essential component of structuring measurement of quality in the healthcare delivery system is ensuring an appropriate mix of subjective and objective measures, process and outcome measures, and measures relating to all elements of service delivery (i.e., primary, acute, behavioral health, and LTSS). Taking this holistic approach to measurement in the VBP arrangement will help NYS ensure a comprehensive look at quality for the wide range of complex needs for people with I/DD.

While the report discusses several possible quality measures that would be effective in measuring outcomes and the member experience, we suggest the Advisory Group consider how those measures are combined to provide a clear and holistic picture of performance.

### **Consumer Experience Measurement**

Empire supports identifying meaningful measures that reflect the quality of services through the individual experience for **all** categories of services (i.e., primary, acute, behavioral health, LTSS). However, consumer experience data is most critical for HCBS due to the lack of claims-based or other objective measures. The OPWDD Transformation Plan (p.11) emphasizes these priorities:

- *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.

Outcome-based measures, not just process measures, are critical to accomplishing these goals for the OPWDD.

The CQL POMS provide a valid and reliable tool to gain perspective on the member's quality of life and how the services and supports received have contributed to those outcomes. For members with I/DD, this data is critical to ensuring that the services and supports delivered meet the member's expectations, goals, and needs, and are truly person-centered. For the (eventual) managed care entities and for the State, these measures will provide comparability and some metrics related to the seven important quality of life indicators selected by the Advisory Group.

However, as a voluntary tool, POMS is only as good as the participation rate. To ensure adequate input for statistical validity across the providers and CCOs, and for the maximum number of entities to participate in VBP arrangements, Empire recommends that the OPWDD determine how it will increase utilization of the POMS tool. As consideration: Will the State make CQL accreditation and use of the POMS a requirement of the CCOs in the RFP? Will the State provide any resources to support the costs related to implementation of POMS? Will there be training and technical assistance available in order to ensure adequate capacity in implementation?

Another recommendation for consideration is inclusion of National Core Indicators (NCI) data as a potential measurement component of the VBP arrangement, to incorporate systemic measurement based upon consumer experience and other data to complement the POMs individual outcome measures identified by the Advisory Group.

We recognize that the State has been participating in NCI since 2007–08. As the State is already invested in the implementation of NCI, the use of NCI data could provide information that helps compare the quality of CCOs to one another. However, for this to work effectively and provide relevant information, the OPWDD would need to purposefully establish unique identifiers to link individual responses to providers, implement a higher sampling rate and a methodology that ensures participation across CCOs.

Additionally, the State may want to consider use of measures from consumer experience tools that focus on physician and other clinical care services, such as the CG-CAHPS. As a population that frequently struggles to access disability competent medical care that meets their needs, understanding the experiences of people with I/DD as they participate with physicians is an important part of the holistic approach in the VBP arrangement.

#### **Empirical Data Measurement**

As the OPWDD knows, the success of any VBP arrangement depends on more than measuring consumer experience. To establish a successful VBP program, objective data are also needed—data that are both delivered to and received from providers, based upon claims or other empirical data sources.

Empire recognizes that harnessing data is key to managing the health of patients, especially those with developmental disabilities. Below are three main considerations for improving population health management:

**Interoperability and openness.** Creating secure and free-flowing information between providers and other stakeholders to ensure that consistent, high-quality care is available to patients regardless of their location.

**Actionable data.** Generating accurate data and valuable insights, with discrete elements that providers can mine easily for trends, will be critical in helping clinicians make better informed decisions at the point of care.

**Patient engagement.** Encouraging patients to take a proactive role in not only exchanging information about their health, but also using that information to engage actively with their care team and adopt healthier habits through wellness programs

Additionally, Empire supports the inclusion of data points that will indicate the overall performance of the CCOs, such as:

- Measures related to community integration/rebalancing; attainment of person-centered plan goals
- Alignment of authorization and utilization of service hours

Empire agrees with the initial measures identified for the domains of Preventative Health, Diabetes Composite, and Medication. We would also like to see the uncategorized measures recommended by the CAG be incorporated. We especially believe that inclusion of care coordination/person-centered planning measure(s) is critically important, and we would encourage NYS to consider the measures proposed by the National Quality Forum Committee on Quality in Home and Community-Based Services to Support Community Living, such as:

- Percent of members who have service plans that are adequate and appropriate to their needs and personal goals, as indicated in the assessment (MLTSS NJ)
- Percent members who report that their service coordinators help them get what they need (MLTSS HI)
- Percent members responding yes to whether a case manager helped you solve a problem that you have told them about (MNCES)
- Percent members responding yes to does your case manager help coordinate all the services you receive (POMP-CMS)

Empire believes that several additional measures placed in category 3 are important to consider to better understand the overall performance of a network of providers/CCO, including:

- 32 People live (and work) in integrated environments (but instead of using POMS, use actual outcome data)
- 34-37 Avoidable Hospitalization measures
- 44 Increase in number of Pressure ulcers
- 54-55 Ob/Gyn measures: mammograms, cervical cancer screenings (which are often lacking in the I/DD population due to lack of accessible equipment)
- 62, 64 Long Term Care Overall Balance/Rebalancing Measures
- 63 Nursing Facility/Intermediate Care Facility Diversion

Because providers of I/DD may lack the ability to collect data on one or more of these critical factors, Empire recommends OPWDD consider a streamlined data collection approach that is uniform across providers, CCOs, and state staff. A streamlined approach would allow OPWDD and CCOs to manage and work with the data in real time, monitor data collection and timeliness, and allow for data mining and analysis that can be accessed by each party for the individuals they serve.

Finally, Empire supports the inclusion of data points that will indicate the overall performance of the CCOs and the ability to compare data across CCOs, such as objective measures related to:

- Community integration/rebalancing
- Attainment of person-centered plan goals
- Alignment of authorization and utilization of service hours

#### **Other Outcome-Based Payment Examples from Our Tennessee Health Plan**

Beyond the value based payment model in the report, we wanted to offer an overview of another approach to outcome-based payment in place with our Tennessee health plan affiliate for potential consideration. On July 1, 2016, Tennessee implemented an integrated managed long-term services and supports (MLTSS) program within its existing managed care demonstration that is specifically geared toward promoting and supporting integrated, competitive employment and independent, integrated

community living as the first and preferred option for individuals with I/DD. The Employment and Community First program has focused on the development of a benefit structure and the alignment of financial incentives specifically geared toward promoting integrated competitive employment and integrated community living that will result in improved employment and quality of life outcomes by paying for milestones achieved by the member. Some of the milestones include career discovery, job placement, job continuity, career advancement, and transition of employment from a sheltered worksite to an integrated competitive job in the community.

Additionally, other employment services will be reimbursed in part on the provider's performance (risk adjusted) on specified employment outcomes in areas such as: the number or percent of persons supported employed in individual employment in integrated settings; the number of hours worked per week; or competitive (prevailing) wages of those supported. All of these incentives seek to assure that providers and MCOs are working together to assure optimal community integration, progression through the employment process, and positive outcomes associated with integrated competitive employment for individuals. Empire believes that these types of outcome-based incentives are an integral component of systems transformation and alternative payment arrangements for individuals with I/DD.

#### **Implementing VBP and CCOs**

As the State considers options for the structure and requirements for the CCOs, alignment with the goals for VBP as articulated in the progress report will be foundational to success of these reforms. Factors such as technology, interoperability between providers, provider staff resources, understanding of financial risk, phase-in, and training are all important in establishing and maintaining an effective VBP arrangement, and should be built into the CCO development process.

As the logical nexus for member attribution, data from CCOs will be critical to the development of VBP arrangements. To ensure the success of the VBP program and the CCOs, Empire recommends that data requirements and infrastructure be established upfront in the CCO procurement. If the State plans to require that CCOs have an established IT infrastructure as part of their application/consideration process, we recommend that OPWDD clearly define the operating requirements and expectations for data systems and interoperability prior to the CCO application process.

We understand the importance of training and educating providers, members with I/DD and their families about the VBP strategies since the interviewing and monitoring tools may be modified for VBP. MCOs have vast experience in implementing VBPs for other provider types and populations, which can assist the state in developing a similar approach for the I/DD providers and population.

If the State could fund or offset the cost of survey completion and technology updates for integrating the necessary tools, then providers will likely be more apt to implement the system changes and adopt the VBP model of payment.

#### **Supporting the OPWDD in Moving Toward System Reform**

As an example of our approach and support of our provider partners, we provide Quality Scorecards to providers with real-time performance data for providers participating in our performance-based incentive programs to help assist providers identify strengths, opportunities, and gaps in care. The Quality Scorecard is based on the quality of health services delivered to his or her Empire members as

The scorecard details which of the quality measures were used to develop the total earned contribution (i.e., which had the highest number of measured members), the scores received for each quality measure, and the total earned contribution and whether the quality threshold level was met.

**Empire is Committed to Partnering with NYS**

As a committed partner to the NYSDOH and the individuals and families who live in NY, Empire believes the work completed so far is an example that all states should follow. As the OPWDD continues to evolve their plan for system transformation, we would be honored to provide additional input if the OPWDD would find it valuable. We thank you in advance for your review and consideration of our comments.

Sincerely,

A handwritten signature in black ink, appearing to read 'Jack Stephenson', written over a horizontal line.

Jack Stephenson  
President, Empire BlueCross BlueShield HealthPlus

## **RESPONSE TO DOH ON VBP ARRANGEMENT FOR ADULTS WITH I/DD PROGRESS REPORT**

As a provider of OPWDD services to individuals with developmental disabilities since 1991, we would like to make the following comments on the IDD VBP progress report issued by the Department of Health on December 20, 2016. Our comments address the potential arrangement of provider networks serving individuals with I/DD who, based on a predetermined set of measures, would share in cost-savings as a group.

1. OPWDD services are not just in the arena of health care services. Coordinating OPWDD services involves really knowing the person and an understanding not necessarily of medical conditions and available treatments, but primarily of individual abilities, dreams, aspirations, the availability or lack of family support and a host of other factors. These are services that speak to the individual's culture, community, preferences and individuality. Some are habilitative but many are not.

It follows naturally that outcomes for OPWDD services cannot be objectively measured in the same way health outcomes are measured. Measurement of many of these items (particularly the POM's) are quite subjective and may be influenced by the perspective of the person taking the "measurement." It can also depend on the mood of the individual on the day he or she is questioned to determine whether a certain outcome was "met." This puts both OPWDD providers and their network partners at a disadvantage if measures such as these are used to determine payments.

2. Unbalanced contribution to the outcomes makes it unfair for each provider type in these networks to equally share in savings resulting from the VBP arrangements. In many cases, OPWDD providers have scant influence on outcomes directly related to health such as avoidable hospitalizations. Conversely, health care providers have very little influence on the personal choices of individuals with I/DD regarding where to live, work, relationships and the like (the POM's). The success (or lack thereof) of one type of provider may not indicate success of the group as a whole and the inability of one provider type to influence the outcomes of another may potentially lead to frustration and little motivation for improvement.
3. In some cases, the measures can diametrically oppose each other. For example, Topic #23 "People exercise rights" would conceivably include an individual's "right" to make personal lifestyle choices such as smoking and eating unhealthy foods. At the same time, per Topic #38, having a BP <140/90, is likewise considered a valued outcome, even if a higher BP is likely a result of the patient's poor lifestyle choices. The result is that rather than working together with a common set of goals, network providers may unwittingly be pitted against each other in trying to achieve differing, though equally laudable, outcomes.

Based on the above factors, the DOH should consider carving out OPWDD services from the VBP network arrangements that are currently being considered for this subpopulation.



## **Comments on "Value Based Payment Arrangements for Adults with Intellectual or Developmental Disabilities - Progress Report of the IDD Value Based Payment Advisory Group"**

submitted by:

Michael Seereiter, President/CEO, NYS Rehabilitation Association  
Ann M. Hardiman, Executive Director, NYS Association of Community and Residential Agencies  
Hanns Meissner, Executive Director, The Arc of Rensselaer County  
Dan Brown, Executive Director, Franciska Racker Centers

### Process

As members of the IDD VBP Advisory Group, we must register our strong objection with the manner in which the "Value Based Payment Arrangements for Adults with Intellectual or Developmental Disabilities - Progress Report of the IDD Value Based Payment Advisory Group" report was recently published. Advisory Group members were not consulted on the contents of this report, nor was the Advisory Group even afforded the courtesy of notice that NYS intended to issue such a report. There are several inaccuracies in the report, where it is suggested that the Advisory Group made final recommendations, which they did not (e.g. page 16, *CAG Categorization and Discussion of Measures – Category 3*, "the advisory group selected a subset of POMs that they felt correlated with better overall care"). However, perhaps more importantly, in the six months since the IDD VBP Advisory Group last met, our perspectives on value-based arrangements have evolved and are no longer accurately reflected in the published report.

### CQL POMS

While CQL and their Personal Outcome Measures (POMs) offer perhaps the greatest hope for improving the value proposition related to supports for people with IDD/DD, we have growing concerns about applying CQL and their POMs in a reimbursement structure. We believe that in monetizing the POMs, we risk losing their inherent value. The POMs are a very valuable set of tools that help push the envelope of the current service delivery system to new places that better address the life outcomes people receiving supports want, but which have not yet been realized by many.

The POMs can really only be used as a measure of how well a support system has positioned an individual to access their goals – not achieve them. Achievement will always remain the responsibility of the individual, not the support provider.

Additionally, it has become increasingly clear how individual POMs can't be considered in isolation, given their inter-relatedness.

Lastly, the POMS currently appear to offer a means by which to qualify more easily quantified outcomes that add value to people's lives. For example, when it comes to work, the CQL POM "People Choose Where They Work" is valuable. However, instead of being a stand-alone outcome on which a payment for services would be based, this POM would likely better serve as a qualifier for other outcomes more closely aligned with independence and decision making authority associated with economic self-sufficiency – like hours worked and wages earned.

### Over-Reliance on Health

Our reservations about a heavy reliance on health outcomes for people with IDD/DD in such a value based arrangement have also grown since the time of the last meeting of the Advisory Group. From a historical perspective, people with IDD/DD have been defined by their disability by the medical community. Services designed with an exclusive focus on a person's vulnerabilities and deficiencies have resulted in the tradition of the segregated programs we now seek to transform. An over-reliance on health metrics risks bending back the service design to the medical model. In contrast to



the medical model, progressive advocates believe the challenges people with IDD/DD face are social in nature. Social aspects of disability are concerned with how to open our communities to difference and diversity. A social model would define a person with IDD/DD more holistically with an emphasis on capacity, not deficiency. In this view, people with IDD/DD have gifts and talents that can be resources for their community. It is crucial that we right-size the medical model emphasis on health outcomes with relationship and meaningful contribution. Full inclusion can only be achieved if community members and service providers focus less on the “illness” and far more on acceptance of diversity.

While many people with IDD/DD have health issues, many others are at least as healthy as the general population. This is not to say that health outcomes are not important, especially for people with IDD/DD who have health concerns. However, if the challenge for inclusion is more social in nature, then our services are less about treatment and more about supporting an individual holistically. An overemphasis on health measures only distorts our view of the individuals and diverts attention away from our primary purpose.

The concept is that the job of providers is to make the “playing field” even for people with disabilities, equal access to social activities, work, independent living, etc. The outcomes for social supports don’t guarantee an outcome and so tying a VBP to it is problematic. We cannot give people equal access.

### Pilots and Testing

NYS made a wise decision to halt the work of the IDD VBP Advisory Group this past summer, after it realized the long road that lies ahead before getting the IDD/DD sector to managed care. Recognizing this, many members of the Advisory Group recommended that value based payment pilots be developed, to allow the IDD/DD sector to experiment with such arrangements prior to managed care implementation. Given the complexity and uniqueness of developing value based arrangements for this sector, we believe piloting and experimenting with these concepts now – in the current fee-for-service structure – is one of the most effective things NYS can be doing at this point when it comes to IDD/DD services and value based arrangements. This is a point Jason Helgerson recognized and supported in meetings dating back to August of 2015.

In addition, VBP that doesn’t have an adjustment for acuity runs the risk of leaving the complicated population on the sidelines. This must be addressed, and pilots and testing can explore supports to the most complicated person on how VBP might work.

### Simplicity

Many people have spoken of flexibility and efficiency as we have planned transformation and the move toward managed care. In keeping with this, the outcomes must be measureable and simple to compile. Complex value based arrangements will distract from the supports needed and the necessary relationship with the person that is developed to accomplish the supports that a person with a developmental disability needs and wants.

### Closing

There is a great deal more work needed before any value based arrangements in a managed care model put providers within the service system "at risk."

For more information contact:

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Comments provided by YAI regarding the Interim Recommendations made by the CAG for IDD  
Value Based Payments

Thank you for the opportunity to comment. With nearly 60 years of experience, YAI is one of the largest IDD providers in New York State and has embraced the person-centered philosophy and Personal Outcome Measures (POMs). In addition to providing long-term services and supports (LTSS), YAI is affiliated with Premier HealthCare which has five Article 28s throughout NYC. These health care clinics are recognized by NCQA as patient-centered medical homes and offer Article 16 services. We offer the following comments based on our long history of providing LTSS and health care to people with IDD as well as our recent experiences with POMs.

First, although we are pleased to see POMs included as a quality measure, we strongly support the development of a standardized instrument that directly assesses the services that are received through the anticipated Care Coordination Organizations (CCOs). The collection of objective data within this realm is especially needed since only a few CCOs are expected to be funded regionally. We also recommend that quality measures include social determinants of health (such as housing, employment, and transportation).

Second, it is important to recognize that the implementation of POMs is both labor intensive and financially costly. If the field moves in the direction of administering this tool with Certified Interviewers (in order to produce reliable data), the State needs to factor in what resources are needed to ensure successful implementation.

Third, the POMs outcomes listed in Category 1 do not include “people with disabilities exercise their rights”. We strongly encourage the State to incorporate this outcome into Category 1. CQL has noted that the opportunity to exercise choice and rights is a strong and positive indicator of overall quality of life.

Fourth, a technological solution is needed to support the integration of health care and LTSS information as well as POMs data. To collect evidence-based data across multiple providers requires a robust exchange of information.

Lastly, although there has been some preliminary discussion related to attribution and people with IDD with regards to DSRIP PPSs, this issue needs to be considered more thoroughly as OPWDD starts the development of Care Coordination Organizations.

**From:** [doh.sm.delivery.system.reform.incentive.payment.program](mailto:doh.sm.delivery.system.reform.incentive.payment.program)  
**To:** [Jones, Kimberly N \(HEALTH\)](mailto:Jones, Kimberly N (HEALTH))  
**Subject:** FW: IDD CAG VBP Comments  
**Date:** Tuesday, April 04, 2017 3:35:20 PM

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**From:** Maggie Hoffman Susan Platkin [mailto:nyselfd@gmail.com]  
**Sent:** Friday, January 20, 2017 2:28 PM  
**To:** doh.sm.delivery.system.reform.incentive.payment.program <dsrip@health.ny.gov>  
**Subject:** IDD CAG VBP Comments

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As members of the IDD Clinical Advisory Group, we are happy to have the chance to offer our comments on the draft interim report.

Control of Supports and Services  
Self- Directed Services: the gold standard

The number of people using Self-Direction with budget and employer authority should be a Category One Quality Measure, as by definition it allows people to most fully control their lives and be part of the community, without the obstacles that congregate and other agency services create. Further, it is clearly an outcome, not a process. (We were surprised that although we discussed this measure multiple times at committee meetings it was not included in the list of those considered by the committee):

We recommend the following Quality Measures that we believe are “clinically relevant, reliable, valid and feasible”

- How many people self-direct with employer and budget authority?
- How many people have changed from other services to employer and budget authority?

These questions will show the outcome both for people entering the system and for those who are already involved with traditional services; the distinction is helpful as there are different issues involved in each transition.

Using POMS as quality measures in VBP

It seems premature to use the POMs indicators as quality measures. In our understanding, when they’re used as part of a formal POMS assessment, the questions are answered by the individual through an open-ended conversation with a trained examiner. If a few of them are extracted and used as a checklist to look at quality, that’s a different application, and can’t be considered as a valid measure. In addition, we would be concerned that examiner bias, or even subtle coercion could easily affect the results.

As supporters of the use of Value Based Payments to move the system forward, we would appreciate the opportunity to discuss these issues in more depth in the future.

Susan Platkin  
Maggie Hoffman  
NY Self-Determination Coalition

The Coalition is an ad hoc group of parents and professionals dedicated to promoting self-determination as an option for persons with developmental disabilities who require support through the New York State Office for People with Developmental Disabilities. The Coalition works to promote positive system change to bring about public policy reform, financial integrity, and ultimately, increased satisfaction for people with intellectual/developmental disabilities. NYSELD members also mentor parents who have questions about self-directed services.

**From:** [doh.sm.delivery.system.reform.incentive.payment.program](#)  
**To:** [Jones, Kimberly N \(HEALTH\)](#)  
**Subject:** FW: Intellectual and Developmental Disabilities Clinical Assessment Group Public Comment  
**Date:** Tuesday, April 04, 2017 3:35:09 PM

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**From:** [REDACTED]  
**Sent:** Friday, January 20, 2017 7:40 AM  
**To:** doh.sm.delivery.system.reform.incentive.payment.program <dsrip@health.ny.gov>  
**Subject:** Intellectual and Developmental Disabilities Clinical Assessment Group Public Comment

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I am not sure you received my original email after going to your response site. Sorry if this is a duplicate but I have no record on myhcomputer that it was sent to you. I am the Co-chair of OPWDD's Task Force on Special Dentistry, Carl H. Tegtmeier, DMD:

In Category 1, #8--Annual Dental Visit: NCQA is out of step and at odds with standards of dental care and the current literature. First and foremost, the standard of care in dentistry for the general public is two examinations per year. In the "Caries Risk Assessment" Tables published by the American Dental Association, people with IDD by virtue of their diagnosis places them at "Moderate Risk" for caries (cavities). In a recent study of 4,732 individuals with IDD at the Tufts Dental Facilities in Massachusetts, the most comprehensive study to date on the oral health status of people with IDD and published in the Journal of the American Dental Association, the study showed those with IDD who were being seen by the Tufts Facilities up to four times per year, had a cavity incidence of 33%. The incidence of cavities in the general public is 22% per the Surgeon General's Healthy People 2020 Report. The study also showed that 98% of those individuals had periodontal (gum) inflammation. There are numerous studies in both the medical and dental journals showing a link between gum inflammation and cardiovascular disease and diabetes. Four commercial insurance carriers have shown a decrease in medical expenditures of 20% for cardiovascular disease and 10% decrease in expenditures for diabetes when there is good gum health and no inflammation which results from good home care. Based on current literature and standards of dental care, the visits should be biannual.

In Category 3 under Preventive Health, there should be a category that all individuals with IDD have an Oral Health Plan that covers all facets of dental care and focuses on home care. You cannot have the "best possible health" if you don't have good oral health and there is gum inflammation. Even seeing a dentist 4 to 6 times a year cannot change the outcome of gum inflammation if home care is not done properly on a daily basis. Without this measure no meaningful changes in health outcomes for dental disease, cardiovascular disease and diabetes will occur, with dollar savings to the system of care, which negatively impacts the goals of managed care and Value Based Payments.



A family-based organization

**Laura J. Kennedy**  
President

**Steven Kroll**  
Executive Director

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Immediate Past President

January 19, 2017

NYS Department of Health  
[DSRIP@health.ny.gov](mailto:DSRIP@health.ny.gov)  
(Electronic submission)

Re: IDD VBP Recommendation Report Comments

Dear Sir or Madam:

Thank you for the opportunity to comment on the Progress Report entitled Value Based Payment Arrangement for Adults with Intellectual or Developmental Disabilities (IDD), dated December 2016. We believe this report is a step in the right direction towards developing a framework for value-based payments that strive to incentivize quality outcomes in the IDD system.

Towards this goal, we would like to share some high level perspectives on the work to date, the report and the measures proposed in the report. We have also provided some feedback on the telephone call held on January 11, 2016 with the Advisory Group to discuss the Progress Report preliminary findings and the overall progress of the work.

### Continued Work of the Value Based Payments Advisory Group

NYSARC requests continued dialogue and discussion about performance measures and outcome in our service system. These meetings have been highly informative and beneficial. In contrast to some of the discussion on January 11, 2016, NYSARC does not believe that we can afford to wait until New York's IDD managed care direction becomes clearer. The Advisory Group should continue to meet and discuss the challenges a VBP system presents in order to be prepared for the future. We think a proactive approach that prepares us for the eventuality of managed care is pragmatic and appropriate given the complexity of developing outcomes in our system that are reliable, valid and agreed upon by providers. The meetings to date have resulted in excellent dialogue about outcome measures, but have also demonstrated how complex these will be to develop and reach consensus in the field.

### Use of CQL Personal Outcome Measures (POMs)

Forty of NYSARC's 47 operational Chapters (85%) are fully CQL accredited. We strive to become the first voluntary organization that is fully accredited and we are close to achieving this goal. Given our knowledge of CQL and the Personal Outcome Measures (POMs), we continue to struggle with the report's recommendation of using, in part, POMs to determine provider payment.

Member: The Arc

NYSARC does not believe that POMs should be used in this fashion and that there is great risk in trying to tie POMs to payment structure. While POMs outcomes are considered individually “valid” and “reliable,” these individual outcomes can be influenced to great extent by external/environmental factors and are simply a snapshot in time of the individual.

Administering a POM interview when someone is having a difficult day will likely result in different scores than when he/she is experiencing a more positive outlook. Given this inherent variability, use of specific POM outcome measures to determine payment would not be an acceptable use.

If the Advisory Group wishes to proceed with CQL metrics, NYSARC believes that a much better determinant of payment would be to use a sample of the 21 POM “presence of supports” measures. As background, all 21 POMs are assessed on two distinct, but related, levels - (1) actual POM achievement and (2) presence of supports for the achievement of POMs. The latter measure assesses whether the provider has the appropriate supports in place to assist individuals in achieving desired outcomes, not whether the individuals actually achieve these outcomes. This is beneficial in instances where a person’s goals/desires may not be realistic or pragmatic when compared with their capabilities. POM presence of supports measures are process-based measures that are within the control of the provider. They are not subject to the fluctuations that may be evident when assessing POMs individual by individual. The presence of supports measures are much more stable and constant compared with the POMs outcome measures.

Furthermore, great thought and discussion will be needed to operationalize the use of either the POMs or the presence of supports measures. For example:

- Will all New York State IDD providers be required to become CQL accredited and use these measures?
- Who will measure these outcomes or the presence of supports in the people we serve? Will CQL certified interviewers be measuring these outcomes and will this be required?
- Will scores reflect aggregated averages from all individuals or a sample of individuals served by a provider? What will that sample be and how would it be selected?
- How will this be funded for providers who are not CQL accredited or for those that are accredited but do not have adequate CQL accredited interviewers available to conduct the necessary numbers of interviews?

As you can see, answers to many questions about applying POMs to a Value Based Payment system are needed prior to any decision or proposal to use such measures to determine payment. Therefore, we question the inclusion of POMs in the Category 1 Measures delineated in the report and have concerns about the use of POMs in a Value Based Payment model.

NYSARC, however, strongly supports the use of a provider achieving CQL accreditation as an incentive payment itself.

#### Additional IDD Outcome Measures

Given the limitations of the CQL outcome measures discussed above, NYSARC believes that additional outcome measures for our field will need to be developed. This is where the VBP Advisory Group can prove to be very valuable.

We certainly think that the National Core Indicators could be leveraged to develop a tool or instrument that might be able to measure individual outcomes across the entire system. However, given the different abilities each individual exhibits, we feel that this will need to be examined in more detail and with a reliability and validity focus to ensure that the outcomes we identify accurately capture the measure of a provider's performance and quality. Members of the Advisory Group recommended that value based payment pilots be developed, to allow the DD sector to experiment with such arrangements prior to managed care implementation and to test reliability and validity. Given the complexity and uniqueness of developing value-based arrangements for the DD sector, we believe piloting and experimenting with these concepts now – in the current fee for service structure is sensible.

Thank you again for the opportunity to comment, we look forward to continuing this important conversation.

Sincerely,



Erik C. Geizer

Associate Executive Director for Quality Improvement and Compliance

cc: Laura J. Kennedy, President, NYSARC, Inc.  
Steve Kroll, Executive Director, NYSARC, Inc.  
Tania F. Seaburg, Chief Policy & Operations Officer, NYSARC, Inc.





**NYCLU**

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January 20, 2017

To: [dsrip@health.ny.gov](mailto:dsrip@health.ny.gov)

Comments on Intellectually/Developmentally Disabled Clinical  
Advisory Group Recommendation Report: IDD Report 12.20.16

We write, on behalf of the 2,699 living Willowbrook class members who are the clients of the New York Civil Liberties Union (“NYCLU”) and New York Lawyers for the Public Interest, co-counsel in the Willowbrook litigation,<sup>1</sup> to offer comments and observations with respect to the Intellectually/Developmentally Disabled Clinical Advisory Group Recommendation Report: I/DD Report 12.20.16, published for a 30-day comment period on December 20, 2016 (“I/DD CAG Report”).

You may be aware that Willowbrook class members range in age from 42 to 100+ and live in each and every region of New York State from the tip of Long Island to the North Country and west to Western New York. The Willowbrook class members receive services in both state-operated settings and in the voluntary-operated settings. The Willowbrook litigation was in the vanguard of the civil rights movement for people with disabilities. Well before the *Olmstead* decision issued by the United States Supreme Court in 1999, the Willowbrook consent judgment mandated that individuals with intellectual disabilities be afforded the “least restrictive and most normal living conditions possible.” This represented a seismic move away from a medical model of care with a robust focus on active treatment, community inclusion, and true quality of life for people with I/DD.

The I/DD CAG Report purports to contain the recommendations provided by the Intellectually/Developmentally Disabled CAG, specific to the Value Based Payment Reform

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<sup>1</sup> In 1972, the NYCLU, with others, commenced the Willowbrook case, a class action litigation in the United States District Court for the Eastern District of New York in 1972, charging that the State of New York had violated the constitutional rights of the residents of the Willowbrook State School. That action, bearing the caption *New York State Assoc. for Retarded Children v. Carey*, Nos. 72 Civ. 356/7, 393 F. Supp. 715 (E.D.N.Y. 1975) (hereinafter the “Willowbrook litigation”), is still pending in the United States District Court before the Hon. Raymond J. Dearie.

program (“VBP”) arrangement definition and quality measures. We understand that VBP models have the dual aim of reducing costs and improving quality of care. A typical VBP approach identifies potential savings by establishing baseline health care costs for specific conditions or populations. The model assumes that the potential for sharing savings generated against the baseline costs will incentivize providers within the network to use more effective treatments and improve outcomes. A key challenge is to document that providers are in fact offering better quality of care and are being paid for value, as opposed to generating shared savings by limiting access to services. To do this, VBP arrangements incorporate performance measures that document health care processes and outcomes, with the proviso that providers can share savings only if specific performance measure thresholds are met.

We believe that it is entirely counterproductive to formulate any VBP recommendations at this point in time, without clarification as to the managed care system that will serve New Yorkers with I/DD that is actually under contemplation or to be implemented.

New York State’s inexorable march towards a system of managed long term care services has been a long one and has taken many turns since it was first contemplated by the New York State Department of Health (“NYSDOH”) back in the mid-1990’s. Indeed, the recently issued FY 2018 Executive Budget Briefing Book Mental Hygiene Chapter indicates that New York State now anticipates that the “OPWDD system will transition to managed care in phases ... Enrollment on a voluntary basis in managed care is expected to begin in 2019, and the transition to managed care is planned to be completed within a five year period.” The naming convention for the I/DD managed care system seems to have morphed from a “DISCO” to a “CCO.”

No further information has yet been made available to the over 125,000 New Yorkers with I/DD and their families and advocates who will be impacted by any redesign of the services delivery system operated under the auspices of the New York State Office for People with Developmental Disabilities (“OPWDD”). Questions have gone entirely unanswered for the past six years about the redesign process and the end product managed care service delivery system for the I/DD population served by New York State. In several important ways, the basic concepts underlying managed care conflict with the principles of consumer choice and control that lie at the heart of self-directed services. Managed care attempts to achieve system-wide efficiencies by consolidating decision-making authority in a single management entity, restricting consumer choice to network-approved providers, and substituting lower-cost interventions for higher-cost interventions wherever possible. The self-direction model, in contrast, vests decision-making authority with the individual receiving supports, with or without the assistance of a designated representative(s). The paucity of specifics on managed care for the I/DD population remains, even as NYSDOH moves ahead designing a statewide Medicaid managed care system.

We also have concerns that the process undertaken in order to developing data driven VBP I/DD quality measures was not, in fact, guided by stakeholders because the data metrics

recommended in the I/DD CAG Report are not appropriate to people with I/DD.<sup>2</sup> The quality recommendations contained in the I/DD CAG rest on almost purely health-oriented requirements, which do little to improve the quality or appropriateness of I/DD supports. The use of a medicalized set of VBP quality measurements simply fail to give adequate weight to the well-developed quality of life measures in which the entire I/DD system and OPWDD's vast array of providers have invested for so many years. The VBP model proposed in the I/DD CAG Report not only fails to "value" quality of life markers but also creates the very real danger that "costly" individuals, such as people with I/DD who require more than minimal care and who will not "improve" or need fewer hours of care over time, will be relegated to nursing homes and other agencies that are not required to provide enough staffing or programming because the rates are not designed to reward agencies that provide a better quality of life for consumers as opposed to simply a reduction of Medicaid costs for New York State. Absent any connection between OPWDD quality assurance/quality improvement data and the recommended measures set forth in the I/DD CAG Report, agencies that provide bad care that does not result in hospitalization and/or other medical utilization could wind up achieving high monetary VBP compensation than agencies that provide quite good "total population care" but whose consumers have higher rates of medical utilization.

It is important to note that because of their often-complex health needs, individuals with I/DD<sup>3</sup> have unique service utilization patterns that differ significantly from the general and Medicaid-specific populations. These health and functional needs, as well as service utilization characteristics, are important differentiators from other populations and should be considered when developing effective and appropriate ways to assess quality of life and monitor the quality of care received. Equally important as this "medical model" is the "social model," which considers individual preferences for where to live, education, employment, recreation, and more.

We offer these cautions to you from a thoughtful and comprehensive white paper published by United Healthcare/Community and State in connection with their series

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<sup>2</sup> As but one example, even with respect to the medical standards invoked in the recommendations, it is inexplicable that certain clinical markers that are prime markers of poor care delivered to people with I/DD, ie urinary tract infections, sepsis, pneumonia, pressure/ulcer sores, and dehydration, are deemed to fall into I/DD CAG Group Category 3 as "insufficiently relevant, valid, reliable, and/or feasible" measures.

<sup>3</sup> Even though individuals with I/DD are often discussed together as a group, there are nuances to each condition that are important to differentiate.

- Individuals with intellectual disabilities have impaired cognitive ability caused by injury, genetic disorder, or neurological challenges. They also have adaptive limitations such as difficulties with self-care and communication.
- Individuals with developmental disabilities have impaired mental, sensory, and/or physical ability and functional limitations in three or more areas (e.g., language, mobility, learning, and self-care), which likely require long-term services and supports (LTSS) or home and community-based services (HCBS).

exploring *Quality: Measuring the Quality of Medicaid Services for People Who Are Aging or Disabled*:

“There are inherent challenges with adapting quality measures for this population beyond the lack of consensus on core measures.

- Current quality measures widely used with other Medicaid populations do not easily translate and address the more complex health care and social needs of individuals with ID/DD.
- Current Medicaid quality measures are generally focused on structure and process and are not more widely focused on individual outcomes and personal experiences, which are the basis for specialized services such as LTSS.
- Quality of life and individual experience perspectives are difficult to quantify consistently given the need to gather data through interviews, surveys, etc. and the subjectivity involved with topics such as quality of life.
- Goals, outcomes of care, and supportive services are personalized and can mean different things to individuals with complex conditions, which makes the use of standardized metrics and tools challenging.”<sup>4</sup>

Finally, the I/DD CAG Report artificially has stacked the deck against utilization of the CQL/POMS measurement standards,<sup>5</sup> by classifying them as process measures when they could easily be outcomes, if stated differently and focused less on the individual’s outcomes and more on the agency’s outcomes with respect to the people those agencies serve. In doing this, NYSDOH would be able to measure and reward the transformation of the OPWDD system while ensuring the agencies are focusing on outcomes for the people they support.

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<sup>4</sup> See *Quality Improvement for Individuals with Intellectual & Developmental Disabilities: A Proposed Framework*, May 2016 available at [https://www.uhcommunityandstate.com/content/dam/community-state/PDFs/NAB\\_ID\\_DD\\_Whitepaper.pdf](https://www.uhcommunityandstate.com/content/dam/community-state/PDFs/NAB_ID_DD_Whitepaper.pdf).

<sup>5</sup> While the I/DD CAG Report notes that the standards are not “mandatory” within the OPWDD system, providers and people with I/DD and their families and advocates believed that the the CQL/POMS quality measures were, in fact, mandated for utilization in the OPWDD system based, in large part on the representations that “OPWDD has embraced the Council on Quality and Leadership’s (CQL) Personal Outcome Measures (POMs) as the person centered quality of life measurement that will be used as a critical quality measure. Personal outcome measures enhance the system to focus on quality from the perspective of the individual receiving services.”

See, e.g. <https://opwdd.ny.gov/opwdd-services-supports/person-centered-planning/personal-outcome-measures>.

While we do not endorse or embrace the CQL/POMS measures, those standards have been nationally normed and are deemed entirely “relevant, valid, reliable, and/or feasible” quality measures.

In closing, we note for the record that there has been significant and well-grounded opposition, across the country and in New York State, to the introduction of managed care for the I/DD population since the early-mid 1990s, among disability advocates as well as many I/DD professionals. In the 1990's as is in fact the case today, media was full of reports recounting the excesses of managed health care, including refusals of necessary services.<sup>6</sup>

Commercial health plans, back in the 1990s [and it would appear today] also discovered that successful cost avoidance strategies in the health care and behavioral health sectors (e.g., minimizing the use of hospital emergency rooms; requiring preauthorization of referrals to medical specialists; and limiting the need for hospital admissions through improved access to out-patient care) were not likely to yield the same savings in the I/DD service sector. With funding tied to wrap-around capitated payment rates, behavioral health plans, for example, had and have strong incentives to minimize the number and length of inpatient admissions to mental hospitals and psychiatric units in general hospitals by investing in expanded outpatient services and using pro-active medication management techniques. But the long-term support needs of persons with intellectual and developmental disabilities are far less episodic in nature than those of individuals with recurring mental illnesses and, consequently, less susceptible to such cost-avoidance strategies.

The development of a valued based payments system to the delivery of long term supports and services on a 24/7/365 basis to people with I/DD must be guided by stakeholders who help develop data driven quality measures. While it is challenging to quantify many of the quality of life measures most important over the lifetime of an individual with I/DD, much work has been done in that area and progress has been made. OPWDD and its stakeholders have made substantial efforts over the years to emphasize person-centered, social support principles when redesigning the system for paying for and delivering services. It is discouraging to see that the I/DD CAG Report does not make better use of all the work OPWDD has done to develop metrics that are outcome based. Those efforts will be for naught if, a managed care service delivery system grounded in cost avoidance strategies appropriate in the medical model is imposed while ignoring measures to improve the quality or appropriateness of I/DD supports. That certainly appears to be so based on the I/DD CAG Report.

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<sup>6</sup> See, e.g., *Medicaid Matters: Mis-Managed Care, Fair Hearing Decisions on Medicaid Home Care Reductions*, available at <https://assets.documentcloud.org/documents/2996191/Report-on-Medicaid-Home-Care-Reductions-in-New.pdf>. This detailed report was prepared by a coalition of more than 100 nonprofit groups who found that since January 2015, Senior Health Partners of Healthfirst and at least two other companies have been systematically cutting the hours of home care to their disabled clients, typically without proper notice or legal justification. By law, only a change in a client's medical condition or circumstance is supposed to allow a reduction.

See also *Lives Upended by Disputed Cuts in Home-Health Care for Disabled Patients*, Nina Bernstein, New York Times, July 20, 2016 available at [https://www.nytimes.com/2016/07/21/nyregion/insurance-groups-in-new-york-improperly-cut-home-care-hours.html?ref=collection%2Fbyline%2Fina-bernstein&action=click&contentCollection=undefined&region=stream&module=stream\\_unit&version=latest&contentPlacement=7&pgtype=collection&r=0](https://www.nytimes.com/2016/07/21/nyregion/insurance-groups-in-new-york-improperly-cut-home-care-hours.html?ref=collection%2Fbyline%2Fina-bernstein&action=click&contentCollection=undefined&region=stream&module=stream_unit&version=latest&contentPlacement=7&pgtype=collection&r=0); and *Medicaid Shift Fuels Rush for Profitable Clients*, Nina Bernstein, New York Times, May 8, 2014 available at <https://www.nytimes.com/2014/05/09/nyregion/medicaid-shift-fuels-rush-for-profitable-clients.html>

Accordingly, we strongly urge the recommendations set forth in the I/DD CAG Report be deferred until such time as the New York State I/DD managed care system is in fact established, or at least explicated, or the recommendations set forth in the I/DD CAG Report be revised in their entirety.

Thank you for your consideration of our comments.

*s/ Beth Haroules*

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*s/ Roberta Mueller*

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## **CONSUMER ADVISORY BOARD WILLOWBROOK CLASS**

1050 Forest Hill Road  
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January 20, 2016

On behalf of the Consumer Advisory Board for the Willowbrook Class, thank you for the opportunity to provide comments on the Value Based Payment [VBP] for Adults with Intellectual and/or Developmental Disabilities [I/DD].

During the past decade, there have been various changes in the OPWDD delivery system and even more discussion on proposed changes - some have gone to the wayside and others continue to garner discussion. Managed care for people with I/DD is one of the conversations that continues to grow. Change does not have to be viewed as a bad thing, yes, it is a challenge to everyone that it presents itself to, but with proper planning and engagement it is more readily accepted. However, as OPWDD and NYS in conjunction with CMS moves towards conflict free care coordination and managed care, there has been a disconnect with the true stakeholders - the men and women who live the lives that we discuss everyday and their advocates. The most recent oversight is that of the VBP for adults with I/DD - less than 10% of the advisory group membership consisted of people who have I/DD or their advocates. Per Alice Lind and Nancy Archibald, in "Structuring New Service Delivery Models for Individuals with Intellectual and Developmental Disabilities" [CHCS 2013 Policy Brief], stakeholder engagement is a "core structural element" when proposing changes to a delivery system. How then can the VBP Advisory Group present their recommended quality measures with confidence while lacking this core element?

It is undeniable that people want to choose where they live, who they live with, what they eat, etc., but without a healthy being, without respect from others and without protection from neglect and abuse - the other categories are irrelevant in a person's life.

The fact that the CAG did not put that both respect and freedom from neglect and abuse in Category 1 is alarming [the notes section reflect a subset was selected that better met overall care]; we respectfully disagree and request that this be reconsidered - without those core qualities in one's life, the others are meaningless. If the question remains as to how this would be measured, data is generated by the New York State Justice Center that could be accessed to determine allegations of abuse and neglect. This same information would reflect on a provider agency and their approach to dignity and respect via the employees they recruit and retain as well as their training modules.

The CAG has adopted recommendations for measurement from our health care system that assist us as we age and our health characteristics change [this is true whether you have I/DD or not] including preventive medical care, blood pressure screenings and colorectal cancer screenings; however, only an annual dental visit is recommended and screenings such as cervical and mammograms are relegated to category 3. It is a standard recommendation that dental visits occur twice a year and as needed, therefore the question has to be asked why would the standard be lower for a person with and intellectual and/or developmental disability? Dental health is crucial to our overall health including but not limited to our cardiac status as we age. Furthermore, cervical screenings and mammograms are both necessary screening tools for women who are sexually active, have familial history of cancer, as well as for the aging female. Perhaps

the decision was based on the fact that these are identified as a “process” vs an outcome, but for a meaningful life, one’s overall health must be evaluated and maintained.

Furthermore, we would like to take this opportunity and stress to the CAG that this is the opportunity to address the unnecessary visits to emergency rooms as well as unnecessary hospital stays and prolonged hospital stays. In 2010 NYS ranked 50th in the country for avoidable hospital use [Value Based Payments in a I/DD Context, Presentation for UCP Annual Conference, The Movement, The Mission, The Magic Betsy Lynam, KPMG, October 17, 2016, [www.cpofnys.org](http://www.cpofnys.org)]. Having to visit emergency rooms, for non-emergency medical purposes, then have to wait due to emergency rooms triaging, *must* be made a priority. Time spent in this untenable situation has the potential to lead to behavioral episodes that would otherwise not occur as well as exposure to illness that may have otherwise been avoided. This is not only a health measurement, but is also a quality of life issue.

To achieve these goals while realigning the Medicaid system we are told that the first step will be to establish conflict free case management - yet there is little public information available on development for this crucial aspect of managed care from either OPWDD or NYS DOH. Nor is there a measurement for this particular aspect of value based payments [notes indicate requires development]. The question must be asked will the care coordinating organization [CCO] be exempt from value based payments although they are the responsible party to manage the person’s life and care? It is our recommendation that the CCOs be held to standards that will ensure quality life factors are developed per the person’s request, ensure that the person has a life whereby they are respected and protected, and ensure that the person is healthy through the use of annual assessments and medically recommended screening tools while decreasing unnecessary visits to hospitals and unnecessary hospital stays. This will be the beginning of a meaningful, healthy life whereby choices made will only be enhanced because they can be enjoyed to their fullest.

We appreciate the opportunity to comment and look forward to the next steps of this vital process as OPWDD with the NYS DOH and CMS continue to propose changes.

Sincerely,

*Antonia Ferguson*

Antonia Ferguson, Executive Director  
Consumer Advisory Board for the Willowbrook Class

cc: CAB