

# Measuring and Improving Quality for New York Medicaid Beneficiaries with Developmental Disabilities

United Hospital Fund—April 11, 2013

## Meeting Summary

### **Welcome and Introductions, Goals for the Day**

*James Tallon, President, United Hospital Fund (UHF)*

*Courtney Burke, Commissioner, Office for People With Developmental Disabilities (OPWDD)*

Commissioner Burke set the context for the day's meeting, stating the focus will be on measuring and improving quality, and noting there is a big opportunity to shape the future. Burke reviewed OPWDD's five principles guiding system transformation:

- Moving towards a more person-centered system
- Moving to Managed Care
- Changing the financing
- Moving people out of institutions
- Changing the way we see quality

Commissioner Burke referred to the recently enacted New York State budget and announced the advisory council charged with identifying \$90M in required savings has reached consensus and was, thankfully, able to avoid cuts to services.

Burke referred back to the December 13, 2012 meeting, entitled *Shifting New York's Developmental Disabilities System to Medicaid Managed Care*, also hosted by UHF. She and her staff decided the best issue to target in a follow-up meeting is quality measurement, which connects well to the other principles.

For the movement of individuals with developmental disabilities into managed care, personal outcomes for individuals are vitally important. Current models do not meet needs or expectations because caring for these populations entails lifetime care. Within that context, Burke outlined three broad questions that need to be addressed:

1. Are the measures we currently have the best ones moving forward?
2. Can we identify synergies between existing measures?
3. How can we expand the use of these metrics and introduce them to the field?

Continuing to set the context for the day's agenda, James Tallon recounted the creation of the National Quality Forum (NQF), which is on its third iteration. NQF exemplifies the evolution of both intent and process, and the importance of persevering through tremendous complexity to keep improving the state of the field.

The triple aim allows us to think about all three essential ingredients of a quality health care system: better health, better care, and lower costs. Broadly defined, better care involves both individuals and populations. More narrowly defined, it represents the well-being of individuals, their experiences, and what is meaningful to them. Achieving lower costs is a constant need that never goes away.

Tallon set the tone for the meeting by stating this is a journey with no specific route, one in which thoughtful people come together to figure out how to create meaningful definitions.

### **Update on NYSDOH Quality Measurement in Managed Long Term Care**

*Pat Roohan, Director, Office of Quality and Patient Safety, Department of Health (DOH)*

Patrick Roohan's office is the focus of all quality work in DOH. He began his remarks by asking the central question of why we measure quality. In the 1990s, when capitation became the norm through HMO products, employers wanted to know what they were paying for, and consumers wanted measures of performance. Quality measurement (QM) became a means of achieving accountability.

In a mature QM system, many things are possible. Roohan outlined current uses for QM, including public reporting, quality improvement, certification and surveillance, identification of higher scoring plans for auto-assignment in managed care, as well as payment increases. Ultimately, QM is a step towards improvement, which helps plans and providers figure out why they are not performing at a higher level.

Roohan recommended that specialized care management for developmental disabilities services use measures that have already been created. For example, he suggested using quality assurance reporting requirements (QARR) as a basis for core measures of medical needs, and then adding specific measures to target the needs of individuals with developmental disabilities.

Roohan drew parallels to the State's ongoing approach to QM for mandatory enrollment in managed long-term care (MLTC). Data for these quality measures are collected from a number of sources, including the Semi-Annual Assessment of Members (SAAM), member satisfaction surveys, and encounter data; the latter is particularly useful in revealing patterns of care. Eventually, once the State's ongoing movement to a uniform assessment survey (UAS) is complete, this satisfaction survey will be a single tool used across programs. For individuals with developmental disabilities, Roohan noted that member satisfaction surveys should include the views of individuals, parents, and caregivers.

Several meeting participants had questions. One individual pointed to the differences between the types of measures used for mainstream long-term care (LTC) services and supports, typically used by frail seniors and adults with physical disabilities, and those needed for measuring quality in developmental disabilities services. Roohan responded that what is being

done for LTC populations is not the answer for individuals with developmental disabilities. However, there is overlap, and DOH can build on any commonality.

Another question focused on the fact that the developmental disabilities system is missing a fundamental baseline of descriptive data; providers need to understand better what services are currently being used. Roohan agreed and drew parallels to what is being learned about beneficiaries with behavioral health conditions. For example, gathering baseline data revealed that the shorter life expectancy of populations with severe mental health issues is related to the many medications that are used in treatment, which can produce significant and often untreated physical health issues.

### **Panel on Quality Measurement and Development Disabilities**

*Sarah Scholle, National Committee on Quality Assurance (NCQA)*

Sarah Scholle discussed NCQA's work defining quality measurement in managed care settings. She pointed out that quality issues will be different for individuals with developmental disabilities because in QM, the same words mean different things for different populations. For NCQA, this context has changed over time. For example, NCQA used to focus on the lack of adequate care, but is now focusing on over-treatment.

QM allows plans and providers to be held accountable, and it can help drive improvement. The goal is to have measures that can show improvement over time. Sometimes, however, this improvement is hard to achieve. For example, with respect to people with behavioral health conditions who have been hospitalized, we have not been able to improve the number of individuals who have an outpatient visit within 30 days of discharge. One of the challenges with moving this measure is that it requires collaboration across settings. It also involves engaging an individual patient who is likely to be disconnected from a usual source of care.

NCQA has spent considerable time looking at people with dual enrollment in Medicare and Medicaid, a population containing many subgroups with varying levels and types of needs. To better understand this population, their first activity was to pull together a group of individuals to define common concerns. Then, NCQA focused on how to measure these issues and how to use the measures to improve care—with the guiding imperative to look at care from the patient's point of view. NCQA recognizes the inherent difficulty in measuring and incentivizing coordination across settings when providers have limited control in the related areas of care. Real-time data sharing across settings would be one way to improve in this situation.

A central question for quality improvement is to define the model of care. Once this is understood, the health plan can then determine *how* to improve quality. A key issue for quality measurement for beneficiaries with developmental disabilities is measuring experiences, not just structures and processes. Structure and process measures, however, are still important for individuals with developmental disabilities, since they will provide a roadmap for plans new to serving this population.

Other challenges for managed care plans in serving beneficiaries with developmental disabilities include building relationships with developmental disabilities providers, information sharing, focusing on functional status outcomes, eliciting beneficiaries' individualized goals, and mapping care to what matters to the individual.

*Cathy Ficker Terrill, Council on Quality and Leadership (CQL)*

Cathy Terrill described her organization's experience with personal outcome measures (POMs)—21 validated metrics used to identify the quality outcomes each individual wants in his or her life and to determine if the supports are present to help the individual achieve the identified outcomes. Terrill believes that these metrics can make an enormous difference for people and for organizations. Providers can use the information gathered from interviews – not satisfaction surveys - to inform care planning as well as to make organizational changes. Most people have 11-13 POMs in their life.

Through her work, Terrill has come to believe that the social relationships and supports people give each other in life are the most valuable because, as she put it, “everyone needs a social network.” Therefore, providers should help individuals with developmental disabilities to develop these networks for themselves. These networks will allow them to have a successful life. POMs can help providers and individuals achieve this common goal.

Terrill also noted that providers will do what is being measured. So, collecting data on something will make providers focus on those things. Recent POMs data indicates that some outcomes depend on connections to external resources. Generally, it shows that safety, security and health are well protected, while things like exercising choice remain a challenge.

*Valerie Bradley, National Core Indicators (NCI)*

Valerie Bradley explained that, whenever you establish a performance measurement mechanism, you are communicating to the field what they should prioritize. NCI measures prioritize understanding system performance rather than individual outcomes. NCI measures are not meant for individual planning, nor should they be used as report cards on providers. Instead, they are meant to be a system level metric to track progress within a state and to compare across states. With NCI, states can compare their performance across 38 states, and in this way, identify patterns and trends nationwide.

## **Q & A and Discussion**

Commissioner Burke opened the discussion portion of the day by reminding everyone that the purpose of the meeting is to address some of the very real challenges we face in developing and using these measures for specialized developmental disabilities services. Participants' comments are summarized below.

- There is concern that developing person-centered measures could become “the work” itself and divert provider resources from actual person-centered services. For some providers who have a close relationship with the individuals they serve, the development and use of these types of metrics will not be as burdensome.

- There are multiple existing surveys; however, the focus has always been on issues like safety and not on an evaluation of how well services address a person's needs. Achieving the latter is harder.
- Process is important because individuals with developmental disabilities have a history of feeling that they are not being heard. It takes a long time to build relationships between providers and individuals. This speaks to the need for a person-centered process, which is often driven by an organization's culture. Measures can be valuable because they provide a guideline for how organizations can develop rapport with the people they support.
- There is over-regulation in the developmental disabilities service system. One commenter said he spends 40 percent of his time doing paperwork. The hope is for OPWDD to create and employ measures without creating a greater regulatory burden. Providers struggle with allocating resources between measurement and system innovation.
- OPWDD recognizes the regulatory system has been site-based and compliance-focused, and that the focus needs to shift to individuals and their quality of life. Regulatory reform initiatives are underway, which include creating some flexibility for providers, training on POMs, and limiting paperwork requirements. Regulation often came about as a reaction to a crisis. Therefore, some regulations may no longer make sense in today's context.
- Currently, we don't know who is able to travel, cook, or administer their own medications. These are things that should be measured so we can better track spending. It would be useful to know how people acquire new skills and the role of the supports they receive in achieving this goal.
- OPWDD is working on an assessment tool that would collect data on functional skills. There is some concern that these metrics may be used to force people to live in certain settings based on their skills.
- Providers often lack adequate information technology resources to handle the tremendous amount of data collection required.
- Unfortunately, true independence only exists in a family setting. For example, in a group home, individuals must follow the directions of their supervisor or face eviction.
- How do we promote a system that will support what payers want? There must be alignment between quality measures and the outcomes that DISCOs will need to achieve.

- Gaps exist in the availability of services; understanding these gaps will give providers a sense of what needs to be fixed. Data will reveal deficiencies in services and can be used to move us forward and achieve progress.
- There was some discussion about whether the 21 POMs can be effective for everyone, including, for example, individuals who do not speak. For these individuals, the provider organization needs staff to get to know the individuals and help customize the outcome measures. Non-verbal responses can be used as well as observation. The use of peer-to-peer communication is also possible.
- POMs are not comprehensive, but provide a solid basis for the interview. Some individuals will only focus on a few of the outcomes, which can be customized with probing questions. Clearly, there needs to be some customization of measures to fit the experience of the people being served.
- There are a half dozen measurement tools in the field, but none of them are aligned. We need an objective entity examining these measures to determine which are necessary and which are not.
- If too many measures are used, everyone is going to be average, which is counterproductive. How do you choose measures, and what are the steps needed to advance this process?
- Providers can capture more data than they think—through things like the billing process. However, most providers are not used to using data in this way.
- OPWDD wants to have a valid and standardized set of measures for DISCOs' care management. One challenge is determining how to achieve this for person-centered outcomes, where different people want different things. OPWDD stated that there is no standardized benchmark that they will be using to evaluate success. They will merely be comparing observed outcomes to goals as stated and defined by individuals.
- Providers want a consistent and valid approach to assessing people's lives. While creating a framework of measures is important, all the metrics may not be valuable or relevant to all the people in the system.
- It takes significant work to explain to families how QM works, and specifically to address their concerns around confidentiality. Families need to understand the value of nationally accepted outcome measures. One way is to describe the outcome measures as the values and priorities parents share and want for their children. Parents also need to see that data collection leads directly to improvement of their child's care plan. The

best way to gain the broader acceptance of the community is to explain that you are doing something that will help to advance the people you serve.

- Family caregivers play a critical role for individuals with developmental disabilities; therefore, quality measures should consider caregivers and their experiences.
- OPWDD hired a culture change director as part of the agency's efforts to instill a more person-centered approach to supporting individuals.
- Currently, providers have a good understanding of measurement at the person level. Now we have to build up to the system level, with composite measures. How to package metrics is a major challenge.

Commissioner Burke wrapped up the meeting with a few closing comments on next steps. OPWDD, in conjunction with the developmental disabilities stakeholder community, must determine what information is most useful to collect and report. Additionally, OPWDD will continue to work towards shedding regulations and seeking objective advice throughout this process.