Welcome, introductions, and goals for the day—James Tallon, president, United Hospital Fund (UHF), and Courtney Burke, commissioner, New York State Office for People With Developmental Disabilities (OPWDD)

James Tallon welcomed the group and framed the day’s discussion. He provided background on the United Hospital’s Fund (UHF’s) role in addressing policy issues in New York State’s health care system, including through the Medicaid Institute at UHF. Tallon expressed his intention for the UHF to serve as a neutral space for discussion of the transformation in the service system for individuals with developmental disabilities. He said the day’s conversation would be an introductory one that would likely continue as the developmental disabilities service system changes.

Courtney Burke couched the context of the day’s conversation as a chance to take a step back and examine broad principles and desired outcomes for the shifts taking place in the developmental disabilities system, even in the midst of ongoing implementation work. With OPWDD nearing final contract requirements and a final Request for Applications for Developmental Disabilities Individual Services and Supports Coordination Organizations (DISCOs), the agency wanted to bring a range of different viewpoints to the table for discussion.

**Context: National Health Care Reform, Medicaid Reform in New York – Tallon**

Tallon laid out four major issues to frame the day’s discussion:

1. New York’s central bipartisan commitment to Medicaid (currently a $50 billion program) as a financing source for a robust set of benefits in New York State, including a commitment to developmental disabilities services that is virtually unmatched nationally.

2. Unresolved debates over the fiscal trajectories of the nation and New York State.

3. Governor Andrew M. Cuomo’s commitment to taking control of the Medicaid program and not letting it dictate the future of the state.

4. A new conversation around care management and care coordination, with different opportunities and tools from those associated with the managed care landscape of the mid-1990s.

**New York’s Developmental Disabilities System: Reform Principles and Strategy – Burke**

Burke outlined the major influencing factors, agency actions, and desired outcomes shaping the redesign of New York’s developmental disabilities system:

- **Influencing Factors**
  - *Olmstead* implementation – Existing systems have hindered community integration and bringing individuals with developmental disabilities into the most integrated settings.
  - *The Affordable Care Act (ACA)* – OPWDD wants the developmental disabilities community to be able to shape ACA initiatives like health homes for individuals with developmental disabilities, rather than have them shaped for the community by other entities.
• Medicaid Redesign Team – OPWDD wants the developmental disabilities community to stay in control of the process as individuals with developmental disabilities are brought into care management.

• Budgets – Budget stresses have been caused by an aging service structure, a lack of flexibility in services, and a minimal increase in the OPWDD budget in recent years.

• Quality Oversight – A major imperative for the state is to measure and improve quality of care and outcomes.

• Agency Actions
  
  o Quality Improvement Plan and Action – Steps have been taken to address quality issues in the DD system.

  o Health and Safety – Many regulations around health and safety in the OPWDD system have been released in 2011-2012.

  o Reorganization – The establishment of OPWDD deputy commissioner Gerald Huber’s Division of Person-Centered Supports has been particularly important.

  o Culture Change – For workers and professionals, OPWDD has prioritized culture change to focus on positive relationships and minimize use of restraints and medication.

  o People First Waiver – OPWDD aims to create a sustainable managed care system focused on person-centered services and choices based on individuals’ needs with transparency in funding. The agency also aims to reduce the number of institutionalized individuals with developmental disabilities significantly over the next five years.

• Desired Outcomes
  
  o Person-centered, self-directed services

  o Integrated, coordinated care

  o Fiscal accountability, sustainability

  o Community integration

  o Person-centered outcome measures

Issues and Challenges Facing the Developmental Disabilities System – Discussion

The meeting participants discussed a number of topics related to the challenges facing the developmental disabilities system. Comments generally fell under the following headings:

• Costs and Resources
  
  o General difficulty experienced by providers in serving a larger pool of people using a shrinking pot of money.

  o An initial infusion of funds needed to account for the costs of transitioning from facility-based care (e.g., development of new services, workforce training, and real estate) in the context of a constrained budget.

  o Challenges faced by providers as reduced funding due to empty “bed slots” threaten solvency and continued provision of services.
- The need to fight to maintain current OPWDD funding in order to be able to reinvest in the service system.

**Person Centeredness and Protections for Individuals with Developmental Disabilities**
- Concern over the loss of the advocacy role that current Medicaid service coordinators (MSCs) play as care coordination transitions into DISCOs managing utilization, with the potential need for an independent ombudsperson to play that role.
- The need for person-centered services to account for changes in individuals’ levels of service need over time.
- Building a platform for self-direction that can accommodate differing levels of family involvement and overcome the notion of self-direction as a “boutique” option.
- Necessity of ensuring that both person-centered planning and respect for persons with developmental disabilities persist across services in both residential and non-residential settings.
- Ensure that the managed care framework is prepared to include families and natural supports.
- Ensure that retirement is an option for recipients of employment services.
- Manage the optics of the People First Waiver around choice and cost containment to avoid backlash against providers to ensure that individuals and families don’t unrealistically expect a free-for-all for services and have their expectations managed.
- Need for a strong, independent appeals process.
- Concern over a potentially lengthy assessment process as well as trepidation that those administering assessments will not personally know individuals or their families.
- Need for students with developmental disabilities to be prepared at an earlier age to transition to life in adulthood.
- Need to better understand the new model of care coordination by learning from Medicaid managed care plans and behavioral health organizations.

**Workforce and Training**
- Need for a more skilled workforce in a world of individualized supports who are prepared to respond to heightened risk and potentially more adverse events in the service system.
- Enhanced training for both provider staff and OPWDD employees around a culture of person-centeredness that encourages choices.
- Reexamination of scope-of-practice laws, including the Nurse Practice Act’s restrictions on nursing tasks performed outside certified settings.
- Difficulties experienced by family members in training new workers as they come into individuals’ home (as they presumably will during the transition to managed care).

**Managed Care Mechanics**
- Need for networks to include specialists equipped and willing to treat people with developmental disabilities.
• Need for cost analyses to reflect the unique needs of people with developmental
disabilities.
• Need for definitions of “medical necessity” to be tailored to individuals with
developmental disabilities.
• Executive training on the financial shift from fee-for-service to capitation.

• Quality Measurement
  • Need for a robust, credible outcomes measurement system with legitimacy.
  • Need for outcomes measures to include the degree to which multiple service choices
    are available as well as satisfaction with those choices.
  • Careful attention should be paid to outcomes around transitions in care as DISCOs are
    rolled out.

• Access
  • Need for awareness of individuals (e.g., individuals on waiting lists or in the justice
    system) who could be served by the developmental disabilities system but currently do
    not have access.
  • Examination of restrictive, prescriptive Medicaid requirements which currently limit
    access to individualized, customized services.
  • Potential for resistance to changes in the service system from individuals and families
    who fought hard to obtain them and fear losing them forever if they transition to
    alternative service options.
  • Lack of access to services in rural areas.

**Shifting to Medicaid Managed Care: Learning from Experience – Carol Raphael, Advanced Leadership Fellow, Harvard University (and former CEO of the Visiting Nurse Service of New York)**

Carol Raphael discussed the transition of the complex populations served by the Visiting Nurse Service of New York (VNSNY) into managed care, with an eye on potential lessons to be drawn for developmental disabilities providers as they move toward DISCOs. The largest home health care agency in the United States, VNSNY has expanded to offer managed care plans across the Medicaid and Medicare programs to over 25,000 individuals dually eligible for Medicare and Medicaid (“duals”), many with multiple chronic illnesses, functional deficits, and cognitive impairments. Those plans are offered through an affiliate, VNSNY CHOICE.

According to Raphael, the primary challenges in creating plans for duals were building infrastructure (e.g., member services, networks, marketing, information technology) and transitioning from fee-for-service payment to capitation. With insufficient membership to command provider discounts through market power, VNSNY CHOICE focused on preventing institutionalization and reducing utilization of unnecessary services in order to contain costs.

VNSNY’s care management model relies on comprehensive health assessments; in-person encounters (including home visits); specially-trained nurse care managers with reasonable caseloads and a multidisciplinary team; self-management education and counseling; and a focus on transitional care. Key elements of the model include a long-term personal relationship between each plan member and care manager; flexible benefits and a culture of doing “whatever it takes;” emphasizing primary care and home care in allocation of premium dollars; and changing practices and relationships.
Raphael emphasized VNSNY CHOICE’s credible performance on member satisfaction, member use of primary care, and reduced hospital admissions. However, she identified challenges around integrating care in the areas of enrollment, capacity to provide complex care management, provider network adequacy, quality evaluation, and effective engagement and protection of consumers. One body that has worked to address those challenges is the Promoting Integrated Care for Dual Eligibles Consortium, funded by the Commonwealth Fund. The consortium works to identify and disseminate best practices among integrated Medicare-Medicaid plans for duals, and promote “scale-up” of high-performing plans.

Raphael addressed several questions from meeting participants with the following responses:

- VNSNY CHOICE is currently piloting sub-capitation with some providers.
- VNSNY CHOICE uses its own assessment tool to evaluate cognitive impairment and has psychiatric consultation available when necessary.
- VNSNY received a planning grant that was helpful in getting VNSNY CHOICE off the ground, but upfront investments and cross-subsidies from other areas of business were necessary in the initial stages.
- New York State offers managed long-term care plans flexibility to tie alternative services (e.g., air conditioner installation) to medical need, and VNSNY CHOICE also has a discretionary fund that it draws on to fund alternative services.
- Break-even levels of enrollment were lower than VNSNY CHOICE initially anticipated.
- VNSNY CHOICE is testing more direct plan-provider communication for health information exchange through the New York eHealth Collaborative as well as emergency department alerts to the plan.
- It took VNSNY CHOICE a significant amount of time (possibly 15 months) to obtain its Article 44 licensure.
- VNSNY CHOICE uses volunteers who call and check in with members to ensure they aren’t too lonely.
- VNSNY CHOICE has successfully piloted remote patient monitoring with 400 patients in the Bronx and is expanding the initiative. It has also seen early success with telehealth in speech therapy.
- Credentialing, licensing, and monitoring providers was a major shift in responsibility to the plan and required a dedicated group of professionals.

Wrap-up and Topics for Future Meetings – Burke and Tallon

Looking forward to future conversations, Burke summarized some of the major themes of the day, including:

- Resource management
- Need for specialists with experience with developmental disabilities
- Balancing the advocacy and utilization management tension in service coordination
- Need for robust quality measures
- Provider flexibility around care transitions
- Person-centered planning
Network development and adequacy
• Shaping expectations
• Educational transitions
• Assessment tools

Potential future topics of interest included the development of quality metrics and an ongoing dialogue with providers with practical experience on transitioning to managed care.

Tallon identified the “business” aspects of the transition, including financial and real estate management, as other themes of the day and potential topics for conversation. He also noted that a clear target for cost containment—like unnecessary hospital admissions in the world of managed long-term care—may not be as clear for individuals with developmental disabilities.

At the conclusion of the meeting, participants offered some final thoughts on themes of the day and future conversation topics, including:

• Gathering and presenting additional data on the characteristics and utilization patterns of individuals with developmental disabilities.
• Identifying robust protections and clear lines of responsibility to address disagreement over individuals’ service needs.
  o Kate Marlay of OPWDD noted that those lines were being more clearly drawn in a contract being prepared to be sent to the federal Centers for Medicare & Medicaid Services (CMS).
• Acknowledging that the choices available to many people will be with whom they already live and who currently serves them, not to live alone.
• Ensuring aging people with can stay in their homes, consistent with Olmstead implementation.
• Changing from a risk-averse system that relies heavily on the executive director and hospital.
• Further discussion of what reinvestment is and how it should be directed.
• Additional discussion on the mechanics of building networks.
• Addressing surplus demand for beds, whether bed space should be maintained, and how the “bed question” factors into rate restructuring.
  o Marlay acknowledged that transitioning services away from beds would take time and said that OPWDD anticipated a two- to three-year transition period.
• Addressing transportation needs.
• The need to assuage fear among families that they won’t be placed on waiting lists for years without services.
  o Burke noted that better services and reasonable costs should not be mutually exclusive, and that effectively balancing these two priorities provided the centerpiece for much of the day’s discussion.