Welcome and Introductions

Betsy MacMichael, Olmstead Plan Stakeholder Advisory (OPSA) Community Co-Chair, opened with a welcome and presided over the meeting. She introduced Deputy Secretary Dave Richard who offered appreciation of the OPSA’s work on behalf of Secretary Mandy Cohen. He then introduced guest presenter Estelle Richman, former Secretary of the Pennsylvania Department of Public Welfare and retired senior advisor to the Secretary of Housing and Urban Development (HUD) for health and human services issues. Ms. Richman presented on the work of the State of Pennsylvania regarding Olmstead planning and implementation.

Estelle Richman’s Presentation

Ms. Richman reviewed “lessons learned” and outcomes from Pennsylvania’s (PA) Olmstead Process. Her main points included these:

- Stakeholder involvement is key; those most impacted must be at the table
- People First language is important
- States should attempt to avoid Department of Justice (DOJ) consent decrees, taking proactive actions to align policies and programs with federal law.
- When a settlement agreement is in place, action and operational results are key to ending the agreement.
- Planning processes provide structure but won’t get a state out of an agreement and will not substitute for enacting a good plan.
- PA took the position that most, if not all, people could live in the community.
- The PA Olmstead Plan guided closure of two developmental centers and three state psychiatric hospitals; skilled nursing facilities were downsized.
- A key component to the plan was tightly limiting admissions to congregate settings and keeping their census very low.
- PA created more Permanent Supported Housing (PSH) under their plan:
  - In I/DD, PA moved from larger, group homes to smaller, two and three-person homes.
  - PA’s Intermediate Care Facilities (ICFs) have been closed or were significantly downsized
- For Nursing Facilities (NF), PA utilized a “buy back” model to get beds offline. They leveraged Money Follows the Person (MFP) funds for younger persons to transition them out of NFs.
Strategies

- What does it take to succeed in Olmstead implementation?
  - Values/Philosophy and Stakeholder Involvement
    - Family and consumer voices must be incorporated into the endeavor
    - Need to involve families and consumers in institutional closure processes.
    - Include guardians at all levels - legal and personal advocates
    - Create a single system of care approach with all systems working together
    - Include providers, hospitals, and NFs to get buy in to move people from facilities to integrated, community settings
    - Create data systems to coordinate the movement of people (e.g., NF, hospital, developmental centers, HCBS providers)
    - Focus on individual needs for housing and services and make their successes the markers for progress and outcomes
    - Talk to users of services and use this as inputs for quality improvement/assessment data
    - “Consumer initiative groups” that are state funded have been key in driving PA’s system forward
    - During PA’s process, they found adults with I/DD often wanted to live with their peers, rather than alone. Master leasing and specialized housing grew in PA as a result
    - Meaningful employment and education options are important
    - Meaningful activities are also key for older adults. “Meaningful” was not partial hospital or group work; it was activities that people cared about.
    - When closing facilities, PA held specific meetings with all stakeholders and continued these until it achieved closures. Communication at every level proved to be key.
    - Flexibility helped PA succeed. Sometimes a plan was laid out and it needed to change along the way, given new information.
    - Work with both advocates in the system and activists outside the system to help push the system forward.
    - Transparency – Being open about all aspects of systems change as you plan and move forward was key.
    - Creativity and risk taking – This was especially true when moving people out of state centers. For example, with an individual with a reputation for being violent, Pennsylvania used a housing model with three staff a day at first and then, over time, reduced the staffing, using a Permanent Supported Housing model with intermittent services/supports and work.
    - The policy was, “Everyone can live in the community. Don’t give up on anyone.” They had a “Plan B” in case the first plan didn’t work.
    - PA created a new advocacy groups for people who transitioned to the community (e.g., “Friends Connection” and “Visions for Equality”)
  - Administrative Capacity
    - Data is critical. Way in which Pennsylvania decided to address failures/problems was informed by data.
- Budget flexibility. The federal Centers for Medicare and Medicaid Services (CMS) regional staff were at the table along the way. This was critical to getting new programs (i.e., waivers or State Plan Amendment (SPA) changes) up and running.
- The State office was also able to negotiate for special funds allocated for new these new programs. They met with the budget office director weekly and, over time, effected revenue enhancements to get Olmstead goals and programs implemented.
- Technical confidence and information technology (IT) capacity were essential. The State developed systems to track people moving out of institutions and to ensure that people had what they needed each step of the way. They monitored to be sure people were able to live successfully in the community and to have full, everyday lives.
- Quality Assurance/ Quality Improvement (QA/QI) – The State made improvements by monitoring data in collaboration with advocates, lawyers and outside evaluators (i.e., Temple University and University of PA).

- **Political Will**
  - A solid communication strategy is key with elected officials. Ms. Richman met with legislators on a weekly basis to inform/educate and to answer questions.
  - Employment was key for those working in facilities. PA was largely able to avoid layoffs. They froze jobs during closures and used job matching to assist those who were going to lose their jobs.
  - They communicated with communities to which people were transitioning to combat the “not in my backyard” (NIMBY) phenomena.
  - They worked closely with unions to ensure key stakeholder buy in.

- **Lessons Learned: What Pennsylvania Found Important to Succeeding with Olmstead Work**
  - Strong communication skills/listening to external stakeholders
  - Setting performance outcomes
  - Listening to all staff at all levels
  - Developing relationships and partners
  - Considering the innovations of others and how they applied to the state
  - Flexibility
  - Risk taking
  - Starting with the question, “What does success look like when developing programs?” and then planning from there.
  - Taking research and evidence-based practices into account
  - Having a good mix of advocacy and activism
  - Taking a “ready, aim and fire” approach. “Don’t get too stuck in planning; you can improve as you go.”

**Questions for Ms. Richman**
- How did you manage roommate match making?
  - Brought people together to see if they “clicked” with one another
  - A lot of trial and error
- Allowed flexibility and time to get the right match
- Made sure the people had a chance to get to know one another (e.g., arranged invitations to dinner)
- Got desired living circumstances for each person (i.e., pets, smoking, etc.)
- Were flexible around number of roommates

- Was staffing more expensive before or after?
  - Staffing costs went down overall and over time
  - Hospital staff moved to staff community treatment teams
  - At the beginning, PA over-staffed because we wanted safety/accountability, so it was more expensive up front. As time went on, the State was able to “right size” staff based on data.
  - During last part of closures, costs went up some because they had to work with staff to get another job, but over time staffing in the community was less costly.

- Do you have examples of how to engage families and guardians who are scared to see people move to communities?
  - Most successful tool was talking with families/guardians. Ms. Richman met with many families in person to talk through concerns.
  - Families who were hesitant talked with families that had moved a family member to the community successfully; this family-to-family connection helped a lot.
  - Ms. Richman also maintained close relationships with National Alliance for People with Mental Illness (NAMI) members.
  - Closing of the PA state hospital was “a painful experience in many ways.” In some cases, Ms. Richman said, families were not supportive of moving. For example, early in the closure process, she had a family that was particularly resistant to transitioning their son to the community. Eight years later, she got a call from the family. Despite the many years of resisting transition, they reported that their son had done well. They had a second son with mental illness as well and, this time, they wanted to talk with Ms. Richman about keeping him out of the hospital. The family noted that their first son had three unsuccessful experiences before he found the community option that worked for him. The story illustrates that patience, flexibility, and communication are key.

- Did PA engage its legislature around capacity restoration rules and, if so, how did this work?
  - There was a lot of discussion around rules and how they were used improperly at the beginning of the process. They had to make sure rules that they did have were enforced correctly. Monitoring data and getting feedback from families let them know what was truly working and what was not.
  - Supports in the system needed to be enhanced while processes around rules were, at the same time, defined more clearly.
  - They had to educate the legislature on the key issues of capacity restoration and involuntary commitment.
  - Downsizing or closing institutions and and building up the Home and Community Based Services (HCBS; Medicaid waiver) system at the same time was key.
PA is a managed care state; they worked “hand-in-hand” with Medicaid to create a good behavioral health (BH) system. The dollars they saved were reinvested in the HCBS system for BH overall. Hospitals admissions have gone down a lot as a result of having a strong, community-based system. Most admissions are short stays to stabilize people (e.g., 3 to 7 days).

PA created two, new tiers of services for persons in hospitals with serious mental illness (SMI):

- A small number of structured residences for people with the most significant needs. Serving up to six people, these settings were designed for people who had required hospital stays, pre-Olmstead.
- In hospitals, they created an “extended acute stay” of up to two months max for those that needed time to stabilize before transitioning to the community.

How did you go about getting satisfaction data from stakeholders in the long term?

- People on the Secretary’s staff monitored Olmstead outcomes
- A state advocacy organization helped as well. The organization formed a Consumer Satisfaction Team. Many of its members are families or people with lived experience. They are independent and can go to any provider at any time to talk to people, assessing satisfaction and learning about what is working and not working. They are a publicly funded organization.

Sherry Lerch - Update from the Technical Assistance Collaborative (TAC)

The TAC contract with DHHS will produce a quantitative and qualitative report to undergird the DHHS’s Olmstead Plan. Ms. Lerch updated the OPSA on TAC’s progress.

- TAC and its subcontractor, Human Services Research Institute (HSRI) will submit the draft analysis to DHHS on March 31
- The data in the report is based upon:
  - Interviews
  - Stakeholder listening sessions
  - Survey Monkey surveys
  - Document review from 2001 to current
  - Data was reviewed through NQI and Uniform Reporting System through SAMHSA
  - Claims data review by HSRI up to data for 2020
- Themes were identified from all these data:
  - In some cases, data refutes what stakeholders may think
  - But in most cases, the findings will not be a surprise
  - TAC’s recommendations are based on the framework for the pending Olmstead Plan, but the recommendations are broad
  - DHHS will take the recommendations and use specific pieces of the report to inform its Olmstead Plan priorities.
- DHHS may be not be able include everything in the first iteration of the its Olmstead Plan, but can use the report as a place to start.
Committee Reports

**Housing** – Mike Bridges

- Graphic describes the committee’s aims, drivers and recommendations, to date.

**Employment** – Bridget Hassan

- Have been meeting weekly
- The workgroup has 4 key targets. We now have a 19-page document that focuses on the following:
  - Increasing competitive employment
  - Increasing employment services for students, to include charter and home school settings
  - Increasing competitive integrated employment as an outcome
  - Increasing the use of best practices and fidelity programs for those in segregated settings or those at risk of entering segregated settings (looking at defining “at risk” currently)
- Committee is working to build out short-term and long-term deliverables around the targets above.
Workforce Development – Jesse Smathers
  o The committee has met 3 times to date
  o 12 to 60 people in attendance at each meeting
  o The committee has heard presentations from several groups around the state who are concerned with workforce issues
  o Have had national and local experts come in and talk, as well as OPSA member Mathew Potter.
  o At this point, these are the primary recommendations:
    ▪ Community Direct Support Worker (DSW) and HCBS workers’ wages need to be comparable to those in state operated facilities and be at a living wage
    ▪ There is a need for career pathways with competency-based tiers and a certification process
    ▪ Tackle the system wide, institutional bias
    ▪ Study how the Earned Income Tax Credit (EITC) may impact workforce issues.

Community Capacity Building - Dotty Foley
  o Ms. Foley was announced as the new chair of the committee
  o Diverse stakeholders from, e.g., the substance use disorder, mental health, Traumatic Brain Injury and Intellectual and Developmental Disabilities (IDD) communities have come to the committee meetings
  o The committee is drafting recommendations that they will complete in April.
  o The committee would like to have more stakeholders and consumers on their group as participation has been low.

Transition to Community – Talley Wells
  o The committee has been meeting monthly with good attendance from OPSA and other community members
  o They have done a lot of education about the number of institutions in the State, across all populations
  o The group has, so far, formulated some strong recommendations, with help from IDD advocates
  o They are working to make recommendations measurable and data driven on both the IDD and Nursing Facility (NF) side.
  o The committee has 22 recommendations to date and is refining those.
  o They are interested in how their recommendations may overlap with those of other subcommittees, such as the Housing and Children, Youth and Families Committees.

Children/Youth and Families - Petra Mozzetti
  o The committee’s first meeting was in September to establish its role and to start working on recommendations
  o Staff turnover in residential settings was among the focal issues for the meeting.
  o In November, at the second meeting, a speaker, Sharon Bell, from the Child Residential Improvement Committee spoke.
  o High Fidelity Wrap Around services and how these services work to keep kids in the community and out of residential settings was the focus of the January meeting.
At end of February, the group held its fourth meeting, featuring Ann Turnbull on the role of families and their needs for support. The committee has also considered how additional housing and services models can be used to support children in the community.

Question:
- How can we educate parents through the school system about available services and lifelong planning, including the HCBS waiver?
  - Holly Riddle offered that this discussion was one between DHHS and the Department of Public Instruction, assisted by advocacy groups.

**Aging Committee** - Steve Strom
- This committee meets the second Friday of each month
- The topics discussed so far include:
  - People with IDD who are aging
  - Aging caregivers
  - TBI
  - Fall prevention
  - Division of Aging and Adult Services State Plan review. The committee would like to determine how that Plan is related to Olmstead.
  - Adult protective services for people with TBI
  - Guardianship issues
  - Aging in place
- The group does not have specific recommendations yet. They want to continue to gather information and have more speakers, but plan to offer recommendations to the OPSA in the coming months.
- Betsy offered to help arrange a dementia and IDD presentation

**Quality Assurance and Quality of Life (QA/QOL)** – Karen Feasel
- The group has been meeting monthly. They have had five meetings thus far.
- They are in the discussion phase and are digesting a variety of presentations.
- The committee has identified the following key principles:
  - QA needs to be built in at the beginning of each policy
  - QA framework needs to emphasize Continuous Quality Improvement (CQI) and Plan-Do-Study-Act (PDSA) approaches
  - National standards need to be incorporated in programs to evaluate success and compare these to other states
  - Population-specific outcomes and measures need to be included in each program
  - QA/QI plans need to be measurable and actionable
- March 16 meeting will be a special presentation on QA monitoring systems by Mathematica, focused on lessons learned from Transitions to Community Living (TCLI) processes for North Carolinians with serious mental illness.
Public Comment

- Several remarks emphasized the importance of the workforce, both competency-based training and equitable, along with the role of community colleges
- Re: 3 to 4 bed group homes: Is there room in the system for these?
  - Ms. Riddle thought that it was too early to comment but noted that PA had employed such settings.

Next Steps for OPSA

- Ms. Riddle noted that the report from TAC will be reviewed at the Department level and released to OPSA.
- Ms. Lerch will talk more about the recommendations in the TAC report in future OPSA meetings.
- OPSA will bring back Leigh Ann Kingsbury, a gerontologist, to talk about aging with disabilities in the Olmstead context.
- Ms. Riddle reminded everyone that the OPSA is open to the public and that DHHS wants to continue hear from all stakeholders.
- Ms. Lerch noted that when the TAC report is released, the work started by the subcommittees will need to continue and become more specific in its focus. She emphasized the importance of legislators hearing about the successes of those who live in the community to help drive the system forward.

Closing Remarks – Sam Hedrick
Ms. Hedrick expressed appreciation for everyone’s efforts and thanked Estelle Richman for her presentation. She then closed the meeting.