

Olmstead Plan Stakeholder Advisory

Quarterly Meeting

May 12, 2021

Meeting Summary

Welcome (Charmaine Fuller Cooper and Betsy MacMichael, Community Co-Chairs)

- Charmaine Fuller Cooper and Betsy MacMichael, Community Co-Chairs thanked everyone for joining the and welcomed members of the legislature who were able to attend today's meeting.

DHHS Leadership Remarks: TAC Analysis (Deputy Secretary Dave Richard, NC Medicaid)

- Deputy Secretary Richard gave opening remarks regarding the Technical Assistance Collaborative's (TAC) report, *An Assessment of the Systems and Services that Support Individuals with Disabilities in North Carolina*, submitted to NC DHHS on March 31, 2021.
- He noted that the report would be a critical input to consider when working on developing the Olmstead Plan.
- Deputy Secretary Richard said that he anticipated positive and negative reactions to the report which was "natural." He encouraged people to be open and to listen to one another. He noted that the Olmstead plan should be factual and represent the reality of the current service system, based on facts and the observations of stakeholders.
- He also emphasized that the plan should reflect people's choices and an array of services and housing in the community. NC DHHS wants the plan to grow and change over time, guiding an evolving service delivery system. Over the next 6 to 7 months, the plan will be developed, the Deputy Secretary said, with this principle in mind.

Overview: Assessment of NCDHHS' Services & Supports for People with Disabilities (Kevin Martone, Executive Director, TAC and Sherry Lerch, Senior. Consultant, TAC)

Overview of Report (Kevin Martone, Executive Director, TAC)

- Mr. Martone provided introductory remarks to frame the TAC report. He thanked NC DHHS staff and all the stakeholders for the information necessary to produce the report.
- He noted that North Carolina is in a positive place, having committed to creating an Olmstead plan at a time when other states have drifted away from the practice. During COVID, it has been challenging but the state has created new ways to do this work and to bring people together virtually.
- Regarding the TAC report, Mr. Martone noted that there may be competing perspectives. TAC's aim, he said, was to examine the system from a broad "community integration lens;" TAC did not seek to represent every issue in the report as a result.
- Mr. Martone closed by saying that that all states face challenges. North Carolina's challenge will be to take the information TAC included in the report; develop an Olmstead Plan; and move forward to support people in integrated settings.
- He turned the presentation over to Sherry Lerch to review the key findings.

Report Findings (Sherry Lerch, Senior. Consultant, TAC)

Information Gathering Process

- Ms. Lerch noted that qualitative data and information was gathered from DHHS Staff interviews, 15 stakeholder listening sessions and an online survey. This represents feedback from about 600 people all total.
- She noted that quantitative data was collected across systems from claims data and other state data. It covers the number of people served by population; penetration rates; the numbers and types of services funded; and service patterns. These data were gathered to augment interviews, listening sessions and the survey.
- TAC reviewed key policies and regulations, along with how dollars were being spent and where. Examples of reports reviewed were those from the Substance Abuse Mental Health Services Administration (SAMHSA), used to compare NC to other states; the National Core Indicators (NCI) reports on Intellectual and Developmental Disabilities services; reports from the LME/MCOs; and other state-generated materials.
- Ms. Lerch noted that these data sources were examined for trends and patterns. TAC also examined “outlier issues,”--those that fell outside of themes--to give a fuller picture of the state’s system.

System Strengths

- Despite the COVID pandemic, the NCDHHS has encouraged people to be engaged in the Olmstead Planning process.
- While there are gaps in *access* to services, generally there is a broad *array* of services and supports
- NC has leveraged mainstream vouchers and rental assistance programs that to help fill the affordable housing gap.
- The “Olmstead preference” under Transitions to Community Living (TCL) for housing units and supports has been successful in helping many persons with serious mental illness (SMI) transition from segregated settings.
- The Governor’s “Employment First” declaration and NC DHHS’ work on Workforce Innovation and Opportunity Act (WIOA) compliance have been positive steps toward supporting employment for persons with disabilities. Under WIOA, NC does not have a waitlist or “order of selection” as do other states.
- State university collaboration with NC DHHS and other state departments is a positive.
- North Carolina is the first state to have developed a Tribal Health Initiative in collaboration with the Cherokee Tribe. The initiative is culturally appropriate in its reflection of tribal principles and could serve as a model for others around the country.
- Medicaid home and community based (HCBS) services are helping to divert people from segregated settings.
- The TCL and Money Follows the Person (MFP) programs conduct in-reach into state-operated hospitals and nursing facilities to help people learn about their options for living in the community. The model for transition services set by these programs is a strength. TCL’s tenancy supports are also a positive.
- Tailored Plan contracts are being prepared to support community integration through the LME/MCOs.
- Evidence-based practices (EBPs), such as Behavioral Health treatment for youth with autism spectrum disorder; Permanent Supportive Housing for adults with serious mental illness; and Medication Assisted Treatment for individuals with substance use disorder are all being integrated into the system.

System Weaknesses

- There is an overreliance on institutional settings, e.g.:
 - DHHS spends a disproportionate amount of state funds (over 50%) on institutional care as opposed to HCBS, particularly in Intellectual and Developmental Disabilities (IDD).
 - The number of people served in the institutions has gone down, but expenditures have gone up.
 - State operated facilities are a default if an HCBS is not available; the “default” often happens due to waitlists and shortages in providers.
 - There is a need for programs and housing in less restrictive settings for people in institutional settings. Often persons with IDD, TBI and physical disabilities stay in these settings for long periods of time.

- There is also a reliance on residential settings that, while in the community, may continue to segregate individuals from the rest of the community (e.g., group homes, adult care homes, Intermediate Care Facilities (ICFs) and Psychiatric Residential Treatment Facilities (PRTFs)). In addition, Day Programs and Adult Developmental Vocational Programs have segregated employment practices, for example, in enclaves and workshops that pay sub minimum wages.
- Regarding LME/MCOs:
 - There are variabilities in service provision across the LME/MCOs; some differences reflect population, but when looking at penetration rates per 1,000 members, establishing comparability across LME/MCOs, there are differences in the numbers of members being served.
 - Rates and service utilization vary across the LME/MCOs.
 - There is not an “evenness” in policies and procedures or in innovative services and supports across the LME/MCOs. A member must live in a particular catchment area to get certain services or innovations in service.

Gaps in Services and Supports

- While some HUD programs have been leveraged to bring more affordable units into the market, there remains a lack of affordable housing across the state. This is true nationally as well. TAC is helping to create a strategic housing plan that parallels the Olmstead Plan work. Housing-related recommendations will be done as part of the housing strategic plan; these will inform the Olmstead Plan as well.
- There are gaps in funding for HCBS for services and populations. For example, crisis services for adults with serious mental illness (SMI) and for children with co-occurring serious emotional disturbance (SED) and IDD as well.
- There is a lack of collective advocacy by people with lived experience across all disability populations as compared to other states.
- There are gaps in pay for direct support workers and other professionals between state operated services/institutions versus HCBS settings and providers. Those in working in institutions are paid more. Training also varies between the two work settings.
- There are disparities in services for people of color and homeless persons who are also over-represented in justice system.
- There are geographic disparities to access to services, particularly to for substance use disorder (SUD) services and housing. There are more affordable housing units in rural areas, but there is a lack of transportation in those areas.
- The data produced by the state is not comprehensive and consistent in a way that allows for data to be used to improve services over time.

Barriers to Community Inclusion

- There is an over reliance on Medicaid waivers, as evidenced by the long waitlists such as that for the Innovations Waiver, compared to the utilization of Medicaid State Plan services.
- State funding is not adequate to cover those not yet under Medicaid expansion coverage. While NC is exploring Medicaid expansion, those not covered lack access to services.
- There is a heavy reliance on guardianships; the restrictions placed on people are a barrier to community inclusion. Alternatives to guardianship, such as supported decision-making, are under-utilized.
- There is a lack of transportation across the state. While telehealth has helped alleviate the lack of access to services and appointments for those without transportation during COVID, telehealth will not ultimately be the best solution for those with high needs.

Recommendations

- Ms. Lerch reviewed the following recommendations from the TAC’s report:

- Build on strengths of the system, such as using models and services from TCL and MFP.
- Increase use of evidence-based and promising practices; target spending to practices with a research base
- Eliminate gaps in community-based services/supports; some examples include additional services for children with IDD and autism and crisis services. Use of block grants and additional waivers, such as those for TBI, could help fill gaps.
- Increase access to affordable housing. Strategies include seeking additional rental assistance for those across disability populations.
- Increase competitive, integrated employment opportunities. Progress has been made in this area. Continuing to help people seek competitive employment and hiring persons with disabilities as peers are some examples of how to continue progress.
- Reduce reliance on institutional settings and reinvest these monies in HCBS.
- Request state bridge funding to expand targeted community-based services until sustainable, long-term funding is established
- Reduce reliance on community-based, congregate residential and segregated day service settings
- Adopt policy strategies to address financing challenges and gaps
- Increase input into development of the Olmstead Plan from under-represented stakeholders
- Create a culture that supports the voices of individuals with lived experience
- Address workforce capacity and shortages
- Use data for evaluation and quality improvement
- Eliminate barriers to services

Creating a Realistic and Actionable Olmstead Plan

- Ms. Lerch noted that developing a plan will need to occur incrementally. Not all populations may be able to be focused on at once. Priorities will need to be identified as a focus for the first iteration of the Olmstead Plan.
- DHHS will need to identify action steps and seek the necessary financial resources aligned with the prioritized goals and steps.
- Other partners should be brought to the table, e.g., the North Carolina Housing Finance Agency, Department of Public Instruction, Department of Labor and Department of Transportation.
- TAC will help support the development of the Plan; its report can serve as a springboard for helping DHHS and its stakeholders think about how to prioritize the steps in the plan. Ultimately, the state will be the main driver as to what is in the plan.

Discussion of TAC Analysis with OPSA (OPSA Members & TAC)

- The Community Co-Chairs opened the meeting for questions and discussion.

Question:

- NC Council on DD Director Talley Wells asked what goals TAC would recommend. He asked how the DHHS would come up with its Olmstead Plan and staff the work. He also asked how the state would handle areas that the report did not cover.

Response:

- Ms. Lerch noted that building the array of services in the community and provider capacity to deliver these is key, along with having integrated, inclusive living options. Doing both simultaneously will be key to making an impact. TAC does not recommend having people leave congregate setting without viable alternatives. Bridge funding is a key strategy to help people transition. She also recommended taking advantage of new federal funding under the American Rescue Act.

- Ms. Lerch shared that other states have created an Olmstead Implementation Office with designated staff to move the process along and report on progress. She also noted that staff in this type of office must be high level and have a direct line to leadership if they are to drive the goals of the Plan forward.
- Regarding what is missing in TAC report, Ms. Lerch noted that TAC did not cover services in education/school-based settings, but she doesn't think this means that the area should not be covered in the Plan

Question:

- Charlene Caraco with Promise Resource Network asked what recommendations TAC had to increase the value of the voices of those with lived experience. She noted that it is often people representing those with lived experience instead of people with disabilities speaking for themselves.

Response:

- Ms. Lerch noted the mantra, "Nothing about us without us." The state needs to make sure they include voices of those with lived experience at the policymaking table; ask their concerns are and include these in action planning. She encouraged all stakeholders to bring people impacted by services to the table and to support them in voicing their concerns.

Question:

- Ray Hemachandra noted that the report inadequately considered the quality of services and education in schools for students with IDD. He asked how to get school systems involved.

Response:

- Ms. Lerch recommended contacting leadership at the Department of Public Instruction and Local Education Agencies involved around children's Individualized Education Plans (IEPs) and other issues for children with disabilities who reside in congregate settings.
- Mr. Martone noted that there has been increased litigation around states' responsibilities for students with disabilities in the Olmstead arena. He encouraged Medicaid to look at their Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefits and responsibilities in conjunction with the Department of Public Instruction.

Comments:

- Michael Maybee commented that the NC Division of Vocational Rehabilitation has done pre-employment transitional services well. NC is a leader in pre-employment transitional services. He wanted to note that this is strong point in their system that can be built on. He wants to see the strengths that have been developed be built about in the Olmstead Plan.
- Virginia Marcus of Disability Rights North Carolina acknowledged the good work to date but urged the state to move from planning to stronger investment in Medicaid HCBS. She observed that the state has long known much of what is in TAC's report and must move forward with MCO contracts that support Olmstead work. The pandemic has made this even more urgent; action should occur, she said, immediately.
- John Nash with the Arc of NC noted that he's concerned about flaws in the report's statements about advocacy. Conversations in Olmstead meetings are often geared toward professional advocates. He's concerned that the standard of "nothing about us without us" is not being met. The Olmstead Plan effort, he went on to say, had not been inclusive of the Arc. He noted that the Arc of NC is key to housing and that he would like to be part of the Housing Strategies work that TAC had referenced. Ms. Lerch noted that the Housing Strategic Plan process is just getting started; TCL's Stephanie Williams said she would reach out to the Arc in the coming months to join the effort. Co-Chair Betsy MacMichael stated the initiative and its partners would work harder to include self-advocates going. Co-Chair Charmaine Fuller Cooper, Ms. MacMichael and Ms. Riddle all provided their contact info in the chat box for people to reach out to address this concern and expressed their commitment to further

assisting the meaningful engagement of self-advocates in the process. Ms. Riddle encouraged all advocacy groups to assist in getting people with lived experience to the table.

- Polly Welsh noted that she does not like the word “disability” and that she prefers terms that acknowledge that people with disabilities have many talents and abilities.
- Matt Potter responded that *not* referring to one’s disability may further stigmatize people because it appears people are “bending over backwards” to be politically correct.

Correction:

- Ms. Lerch noted that the TAC report said House Bill 346 had been *enacted* to provide 5 million dollars for persons with Down Syndrome. The language should have said the Bill was *introduced*. This will be corrected in the final version of the report.

Committee Reports (OPSA Committee Chairs and DHHS Staff)

Housing Committee Update

- Committee Chair Mike Bridges provided the update for the Housing Committee. The group is developing a strategic housing leadership group and plan to do interviews and focus groups over the summer.
- They are in the process of crafting questions for the focus groups.

Employment Committee Update

- DHHS’ Chris Egan gave the update and noted that the committee is identifying priorities and have developed a set of guiding principles
- The principles are Hope, Inspire, Reflect data, Employment; these are “personal and real,” he said, and form the acronym, HIRE.
- The committee has four goal areas that reflect these principles:
 - People with disabilities have competitive and integrated employment.
 - Increase number and the opportunities of students receiving transitional services through collaboration and participation of the local school systems to include charter, private and home school settings.
 - Promote informed choice to enhance competitive integrated employment as an outcome.
 - Assure appropriate funding to implement fidelity modeled Employment programs and best practices for individuals with disabilities who are in or at risk of entering a segregated employment setting.
- The group wants to build on the momentum of NC’s Governor naming the state an “Employment First State.”
- June 9th is the next Employment Committee Meeting

Workforce Development Committee Update

- Committee Chair Karen McLeod noted that the committee did not have any updates since holding the last meeting

Transition to Community Committee Update

- NCCDD’s Talley Wells reported that there are 21 recommendations, to date, from this committee. They have sent these out through Ms. Riddle for feedback from the larger OPSA group.
- The feedback to date has been around ensuring access to the community and the supports and funding necessary to meet goals.
- The committee seeks more input from the Capacity Building Committee to be sure that the work of the two committees complement one another.
- In addition, they would like feedback on is from the Centers on Independent Living (CILs) as to needs to divert people and transition them from both nursing facilities and psychiatric residential treatment facilities (PRTFs).

- The committee has not yet set a next meeting date.

Children Youth and Families Committee Update

- Committee Chair Chandrika Brown stated that their work has centered around out-of-home placements. They have had presentations on community-based alternatives to these. They have gotten up to date information on the number of out-of-home placements in the state as well.
- The committee is in the process of setting up another meeting but does not have a date yet.

Community Capacity Committee Update

- NC Medicaid's Kenneth Bausell advised that this committee submitted recommendations to Ms. Riddle and TAC in April. Now that TAC report has been released, they look forward to integrating their recommendations with TAC's. Mr. Bausell noted that many of this committee's recommendations are in line with the TAC report, particularly regarding building capacity for HCBS.

Older Adults Committee Update

- Division of Aging and Adult Services' Hank Bowers advised that the Older Adults Committee has had six meetings to date.
- Areas of concern include:
 - Aging persons with Traumatic Brain Injury (TBI)
 - Falls prevention as a means of supporting people staying in the community
 - The state's Aging Services Plan as it relates to Olmstead concerns
 - Access to HCBS for aging adults with disabilities
 - Alternatives to guardianship
 - Adult protective services as it relates to Olmstead
- The next meeting is this Friday 5/14 with a presentation by Leigh Ann Kingsbury, a gerontologist with expertise in aging in place.

Quality Assurance and Quality of Life Committee Update

- Chair Leza Wainwright stated that this committee last met in March
- Prior to that, they had a presentation from Mathematica on the development of outcomes for TCL from its data base. Mathematica's presentation assisted the committee in thinking about how to structure data management, data dashboards and quality improvement data.
- The committee sees the foundation of Mathematica laid out as a basis for developing progress measures for the broader Olmstead effort.

Public Comment (Guests/Members of the Public)

- Ms. Riddle noted that the department welcomes all stakeholder input, including written comments. DHHS is setting up an independent email for these purposes. She reminded attendees that all meetings of the OPSA and its committees are open to the public and include time for public comment.
- Christina Dupuch discussed the Registry of Unmet Needs. The Council on Developmental Disabilities is doing interviews with other states regarding their waiting list management issues. Many states, she remarked, have commented that grassroots advocates and organizations must come to the table for progress to occur. She reiterated that there is something still missing in the NC system with respect to the meaningful engagement of advocates in public policymaking. Most of the state's stakeholder groups, for example, are not 50% consumer in composition.

- Co-Chair Fuller Cooper noted that anyone can share the TAC report, collect feedback from others and offer feedback.
- Julie Whitaker, a member of the National Alliance on Mental Illness (NAMI) of NC, noted that NAMI NC had identified Davy County's housing disparities. She asked if this were the case with other counties. Ms. Lerch responded that the report appendices have information for housing by community and that it may answer the question. Co-Chair MacMichael also noted the "hot spot map" that shows, by county, the demographics of different communities.
- Michael Maybee commented that the options we choose are on a bell curve. He cautioned that we not tell families and persons what is best for them. Mr. Maybee cited Justice Ruth Bader Ginsburg's language in the Olmstead decision that, he stated, "emphasizes choice" (citing to the Court's language that community-based services must be provided when the affected persons do not oppose them). Mr. Maybee stated that he wants to make sure that we aren't telling people what is best for them if what they choose to remain in a more restrictive setting.

Next Steps (Holly Riddle, Olmstead Manager, DHHS)

- Ms. Riddle thanked OPSA's Community Co-Chairs for facilitating the meeting. She noted that Olmstead Program Manager Vickie Callair Vickie.Callair@dhhs.nc.gov manages an Olmstead Listserv. She encouraged people to join the listserv and have others who are interested to join as well as a means of staying updated on efforts.
- Ms. Riddle noted that the draft Olmstead Plan will be available for public comment before its release in December of 2021.
- At the May 25th meeting of the OPSA, DHHS will ask for OPSA to use the TAC Report as a springboard for a discussion of priorities for inclusion in the Plan.
- On June 2 at 1 PM, OPSA's Housing Committee will host a special presentation on the HCBS Settings Rule.
- Ms. Riddle again encouraged those attending to join DHHS in reaching out to persons with lived experience and supporting their involvement in all aspects of the Olmstead Plan development process.

Closing Remarks (Betsy MacMichael, Community Co-Chair)

- Co-Chair MacMichael closed out the meeting by saying that she understands the frustration that the state has not advanced certain changes before now, but urged OPSA members to stay motivated and to participate
- Ms. Riddle thanked everyone for attending and thanked TAC for their work on the report.

OPSA Leadership and Staff

Community Co-Chairs – Charmaine Fuller Cooper and Betsy MacMichael

Departmental Co-Chair – Dave Richard, Deputy Secretary for NC Medicaid

Office of the Sr. Advisor for the ADA – Sam Hedrick, Director

Housing – Mike Bridges, Chair (Staff - Stephanie Williams, Pam Lloyd, Ken Edminster)

Employment – Bridget Hassan, Chair (Staff - Julie Bloomingdale, Jeff Stevens)

Workforce Development – Karen McLeod, Chair (Staff - Jesse Smathers, Janie Shivar)

Transition to Community – Kerri Eaker, Chair (Staff – Monica Harrelson, Talley Wells, Katie Visconti)

Children, Youth and Families – Chandrika Brown, Chair (Staff – Petra Mozzetti, Shauna Shaw, Rob Morrell)

Community Capacity Building – Dotty Foley, Chair (Staff -Tamara Smith, Mya Lewis, Kenneth Bausell)

Older Adults – Lanier Cansler, Chair and Former DHHS Secretary (Staff - Hank Bowers, Steve Strom)

Quality Assurance/ Quality of Life – Leza Wainwright, Chair (Staff – Karen Feasel, Drew Kristel)

DHHS Olmstead Manager – Holly Riddle

Office of the Sr. Advisor for the ADA/Olmstead Program Manager – Vickie Callair