North Carolina Olmstead Plan Stakeholder Advisory Committee (OPSA) Meeting July 8, 2020; 2:00 PM – 5:00 PM via Zoom Meeting Summary

OPSA Committee Member Attendees:

DHHS Divisions/Offices

DHHS Olmstead Managers

- Holly Riddle
- Vickie Callair

Office of the Secretary

- Kody Kinsley
- Dave Richard
- Sam Hendrik

NC Medicaid

- Sandra Terrell
- Deborah Goda

Division of Mental Health, Developmental Disabilities and Substance Abuse Services

- Victor Armstrong
- Michelle Laws

Division of State Operated Healthcare Facilities

• Helen Wolstenholme

Division of Vocation Rehabilitation

- Kathie Trotter
- Division of Social Services
 - Susan Osbourne

Division of Aging and Adult Services

• Joyce Massey-Smith

Consumer, Family and Advocacy Group Representatives

NC Council on Developmental Disabilities

• Kerri Bennett Eaker

Alcohol and Drug Council of NC

- Kurtis Taylor
- National Alliance for People with Mental Illness/NC
 - David A. Smith
- Brain Injury Advisory Council of NC
 - David Forsythe
- State Consumer and Family Advisory Committee
 - Benita Purcell
- Disability Rights North Carolina
 - Bryan Dooley
- Statewide Independent Living Council
 - Melea Williams

First in Families

Betsy MacMichael

Arc of NC

- Jeff Smith
- Sibling of a Person with an Intellectual Disability
 - Janet Daniels-Breeding
- Coalition on Aging
 - Charmaine Fuller Cooper
- Dementia Alliance of North Carolina
 - Lanier Cansler
- NC Collaborative for Children, Youth and Families
 - Chandrika Brown
- NC Empowerment Network
 - Matthew Potter
- NC Mental Health Planning and Advisory Committee
 - Jeff McLoud

Promise Resource Network

- Cherene Allen-Caraco
- **Disability Rights North Carolina**

Corye Dunn

Office of the Governor, Deputy Director of Outreach

• Matty Lazo-Chadderton

Professional Organizations and Agencies

NC Housing Finance Agency

• Paul Kimball

NC Association for Persons in Supported Employment

- Bridget Hassan
- NC Providers Council
- Wilson Raynor

Benchmarks

Karen McLeod

Trillium Health (LME/MCO)

• Leza Wainwright

Cardinal Innovations (LME/MCO)

• Mike Bridges

NC Senior Living Association

Jeff Horton

Developmental Disabilities Facilities Association

• Peyton Maynard

Association for Home and Hospice Care of North Carolina

- Tim Rogers
- NC Health Care Facilities Association
 - Adam Sholar

NC General Assembly

- Senator Joyce Krawiec
- Senator Gladys Robinson
- Representative Carla Cunningham

Welcome and Charge of the OPSA

- Holly Riddle, Olmstead Manager with DHHS thanked everyone for joining the meeting. She introduced Kody Kinsley, DHHS Deputy Secretary & OPSA Departmental Co-Chair who reviewed the purpose and charge of the OPSA.
- Deputy Secretary Kinsley thanked all members of the OPSA for their commitment to the Olmstead planning process and for joining today's meeting, particularly while also continuing to respond to COVID-19. He noted that the timing of the work feels especially important as this year is the 30th anniversary of the Olmstead decision.
- The Deputy reviewed that the key purpose of the Olmstead decision: to allow persons with disabilities to live, learn, work, play, and retire alongside others without disabilities in the communities of their choosing. The purpose of this group is to get advice and insights from OPSA members to understand gaps and challenges with navigating current systems, as well as to assist DHHS in developing its plans for the future. He stressed that the process of developing North Carolina's Olmstead plan will be done together, that it will be an ongoing process, and that the plan will serve as a roadmap to greater community inclusion.
- Finally, the Deputy called for OPSA members to engage in the process genuinely and to listen to other members' points of view. He noted that recommending priorities for the plan will be part of the process, as will creating buy-in across stakeholder groups impacted by the plan.

Introduction of Community Co-Chairs and Member Orientation

- Sam Hedrick, Senior Advisor for ADA and Olmstead in the Office of the Secretary, introduced herself and then introduced Charmaine Fuller Cooper who is the Chair-Elect of the North Carolina Coalition on Aging and Betsy McMichael, outgoing Chair of The Coalition, and the Executive Director at First in Families.
- Charmaine and Betsy will be the Community Co-Chairs for the OPSA who will lead the OPSA process, assisted by DHHS Olmstead Manager Holly Riddle.
- Charmaine reviewed the ground rules of the OPSA, including:
 - Patience with varying levels of familiarity with the technology platform (Zoom)
 - Mute phones when you are not talking
 - $\circ~$ If joining by phone, don't put the call on hold as hold music comes on which everyone can hear
 - \circ ~ Use the "raise your hand" feature if you'd like to ask a question or make a comment
 - Use the chat feature if you'd like to communicate throughout the meeting
 - Please say your name before you speak during the Q&A section

Member Orientation

• Holly Riddle presented information on the Olmstead planning process. See PowerPoint, attached, for key points.

National Perspective

- Holly introduced Kevin Martone, Executive Director, Technical Assistance Collaborative (TAC), and Sherry Lerch, Senior Consultant with TAC who, along with the Human Services Research Institute (HSRI) will be consulting to DHHS throughout the Olmstead Planning process.
- Kevin and Sherry presented a PowerPoint outlining the following:
 - The national context for Olmstead plan development
 - Keys to successful planning processes for Olmstead plans
 - $\circ~$ TAC's approach to data and policy analysis for DHHS
- See the PowerPoint attached for key points of the presentation.

Questions & Answers – OPSA Members and Guests

Question: Is there a national percentage balance for baseline funds? (guest) **Answer:** There are some national percentages to benchmark against for people in Long-Term Supports and Services (LTSS) and psychiatric hospital settings. (Kevin Martone, TAC)

Question: I am wondering if we can be provided an overview by DHHS as to why NC hasn't been effective in moving forward with expectations of the 2012 settlement with the Department of Justice (DOJ). In 2017, DOJ said that NC has repeatedly failed to comply with the agreement. What were the barriers to being successful in that plan that we need to overcome to make any new plan effective? (Member, Karen McLeod, Benchmarks)

Answer: Sam Hedrick, Senior Advisor for ADA and Olmstead) responded:

- DHHS has partnered with the NC Housing Finance Agency and it has taken time to build up the housing supply. There are currently 2,700 people living in community housing, based upon a June 30th point in time (PIT) count. Housing reserves are being built with an additional 440 mainstream vouchers added to the housing stock.
- Community Support Teams (CST) and Permanent Supportive Housing (PSH) have been introduced. Training for providers now occurs every 90 days for all providers that participate in CST and Assertive Community Treatment (ACT) services to help people in PSH. Training covers topics such as Fair Housing practices. Progress is being made to increase the number of people receiving Individual Placement and Supports (IPS)/Supported Employment (SE).
- The Transitions to Community Living Initiative (TCLI) has started a new pilot that is showing progress with IPS/SE. plans to roll that out across the state to help additional people with mental illness move to the community. We are working with CCNC to build a better plan for persons with chronic illnesses as well.
- We feel we are coming close to our overall goals for the Settlement Agreement for its end date of June 2021.

Question: The Promise Resource Network and Peer Voice NC has collected data on involuntary commitments (IVCs) across all counties in the state and has found that there has been a 50% increase in involuntary commitments over the last 10 years. In 2015, for example, there were 110,000 incidences of involuntary commitments which did not include Emergency Departments (EDs). The data are difficult to get and historically there has been a lack of interest in looking at how to reduce IVCs. Will this be a focus of the Olmstead plan and is there interest in looking at trauma-informed alternatives and other community alternatives? (Member, Cherene Caraco, The Promise Resource Network)

Answer: We will look at these data points and NC trends and assess against national trends as part of the data analysis for the plan to learn what is contributing to the increase in IVCs. (Sherry Lerch, TAC)

Question: Does the Technical Assistance Collaborative (TAC) have any examples from states who are doing well with deinstitutionalization for those with mental health and substance use disorders (MH/SUDs) and persons with Intellectual and Developmental Disabilities (I/DD) that we as OPSA members can study for insights? Any literature that can be sent our way would be helpful. (Member, Mike Bridges, Cardinal Innovations LME/MCO)

Answer: During this process, we can bring examples from other states that have faced similar challenges. TAC can huddle with state folks, such as Holly and Sam, to help distribute literature to the group on topics of interest throughout the process. (Kevin Martone, TAC)

Question: The Registry of Unmet Needs - Innovations Waiver list is growing. Will this plan address the needs of that population? (Member, Kerri Eaker, NC Council on Developmental Disabilities) **Answer:** We are aware of this registry and it will be one of the data points we will examine and discuss with the Department and stakeholders involved in the planning process. (Sherry Lerch, TAC)

Question: I saw the planning process will be 18 to 22 months. Can you go back into the timeline and give an overview of what this means for the OPSA's involvement? (Tim Rogers, Association for Home and Hospice Care of North Carolina)

Answer: We are seeking to produce a plan in 18 to 22 months. We will discuss in greater detail, after this call with TAC and with co-chairs and department staff, the details of that timeline. We intend for the plan to be a living breathing document. After the plan is completed, the OPSA will be brought back together to review progress and update the plan as needed. (Holly Riddle, Olmstead Manager, DHHS)

Comments/Question: Related to the information Cherene shared, we should also be deliberate about guardianship as well and removing decision making from people. The Department has done some work over the past four years and I hope, as part of this process, we can continue to look at the statutory processes around guardianships and local-level, public guardship practices among Department of Social Services (DSS) staff. We need to continue this and look at public guardianships with contract agencies and DSS staff who are making substituted decisions. (Member, Corye Dunn, Disability Rights North Carolina). We need to look at this as there is often a lot of substituted judgment and termination parental of rights. Has there been any reconsideration in the TCLI settlement to include those with IDD? (Member, Cherene Caraco, The Promise Resource Network)

Answer/Response: Sherry noted that TAC will look at trends and themes as part of the environmental scan and look at critical outliers, and present these as part of the assessment and data gathering process. Kevin noted that, in addition to guardianship issues, conservators may also present a barrier for people to move from Nursing Facilities. TAC can help in thinking about upstream interventions so that the system is not crisis-based, leading people to being in institutions. (Sherry Lerch and Kevin Martone, TAC)

Comment: We need to look at and learn from how the State has addressed [the CMS] Home and Community-Based Services (HCBS) standards in housing choices. This has forced providers to think outside the box, to make things more inclusive for everyone. I just want us to remember that one size does not fit all. (Member, Benita Purcell, State Consumer and Family Advisory Committee). **Response:** Thank you for this comment, it is particularly important within the context of COVID-19. We appreciate this comment. (Charmaine Fuller Cooper, OPSA Community Co-Chair) **Comment:** Since we have some legislators on this call, it's going to take a lot more legislative action in the best interest of disability populations to make the Olmstead efforts effective. Some examples of things that will need to be supported at the legislative level will be to improve access to accessible housing and public transportation. (Member, Matthew Potter, individual with a disability) **Response:** Coming together and choosing priorities is key. There will not likely be sufficient human or financial resources to address all needs across systems and a phased approach will be necessary. (Sherry Lerch, TAC)

Question: Will access to technology be part of community inclusion? What about ICCD Clubhouse access? This is a segregated setting, but it is considered a best practice. How will this setting be viewed in this process of Olmstead planning? (Member, Cherene Caraco, The Promise Resource Network) **Answer:** A positive impact of COVID has been the increased use of technology to deliver services, thereby increasing access. We can also look more broadly at assistive technologies to help people live in the community. We can look at opportunities to use technology as these are brought up by the OPSA. Concerning clubhouses, the idea is that if someone chooses a clubhouse, they can have access to that service, but that this not be the only choice of setting that they have. There is a variety of choice of employment settings, including competitive employment. (Sherry Lerch, TAC).

Vision and Mission

- Betsy MacMichael facilitated a discussion of a vision and mission for the Olmstead plan.
- Attendees suggested a vision includes a world with/that:
 - o Equality
 - Opportunities for all
 - \circ Choice
 - Moves from institutions to a systemic approach to enable all in NC with disabilities to live full and meaningful lives in the community
 - o No barriers to choice
 - With no limit on a person's ability to heal, grow, live, work and love based on their choosing
 - o Value and support of personally defined pursuits of quality of life
 - Full inclusion
 - A North Carolina where all individuals with disabilities can live life to their greatest potential
 - Equal access for all North Carolinians to engage in their community with regard to ability or disability
 - \circ Full potential
 - $\circ \quad \text{No wait lists for services and supports}$
 - \circ $\;$ People are free to choose where and when they move within the community
 - People with disabilities in North Carolina can live lives of their own choosing in the places and with the people they choose
 - An identity that is not "mental patient," "homeless," "disabled," "felon" or "addict"
 - Where a person can choose and live their best life
 - o First-class citizens rather than second or third
 - NC is a community of partnerships where individuals are able to access needed services to help make them successful in life
 - \circ $\;$ Live and not just be surrounded by services

- Opportunities to heal and recover, to live ones' best life and strive for quality of life they desire
- A North Carolina where all individuals with disabilities have the opportunity to live life to their greatest potential.
- Services = benefits
- o No capacity issues
- With respect for every person with disabilities
- o Services that support [one] to realize chosen life outcomes
- An NC where all people can support and flourish in their communities, and their communities can flourish and support all
- To proudly live my truth
- Per [H. Rutherford] Turnbull, "an enviable life"
- Inclusive communities are places where every person with disabilities chooses where to live, who to love, and has opportunities to work, play, and worship as they choose.
- With equality for all
- Where the greatest service to my community, is me
- Attendees suggested a vision that includes a world without:
 - The word "disability"
 - o Stigma
 - o Prejudice
 - o Imposed limitations, confinement, force and coercion
 - \circ Parents who worry about how their grown children will live after they are gone
 - Healthcare discrimination
 - o Inequity based on race, socioeconomic status, gender or sexual identity or disability
 - \circ Unwanted loneliness
 - o Imposed guardianship
 - Harmful interventions that are labeled as treatment (seclusion, restraint, guardianship, etc.)
 - Limits put upon us by others
 - o Disparities
 - Hunger, poverty and discrimination
 - People who don't see past my disability and don't see my abilities
 - Attendees suggested mission statement ideas as follows:
 - \circ $\;$ To make a difference in the lives of the people we support
 - The purpose of the NC Olmstead Plan is to create an inclusive North Carolina that encourages opportunity, equality and inclusivity for those with disabilities to work, live and enjoy their lives to the fullest extent.
 - To enhance wellness, healing, recovery, resilience and quality of life
 - Develop a plan to promote equal opportunities to live, work, and play in communities of their choice
 - To include ALL individuals into the communities of their choice; to respect and value ALL of our neighbors and the ways that they contribute to a better society
 - All people have the right to voice, choice, freedom, and access to resources that advance their well-being, resilience, recovery and healing

- Enact a person-driven human service system to enable all people served to enrich community life
- o A plan to transition NC to a system with the supports necessary for all to live in community
- \circ $\,$ Create a world where every person can see their dreams come true
- \circ $\;$ The dignity of risk and the right to try and explore our own ideas and dreams.

Public Comment

Question: Regarding gaps in services in IDD supports, I am wondering if there is a lack of measurement for services. Does the committee foresee putting some recommendations on how to measure supports for IDD? (guest)

Answer: TAC sees a lot of variation across states in the availability of data for Olmstead planning and performance assessment. This committee can help to determine if the data available is the information you want to know. As part of the process in NC, we can take a look at what data is being collected and, if there are gaps, we can make recommendations on how to better measure and collect data. (Kevin Martone, TAC)

Comment: The partnerships needs to include service providers since they play a critical role in facilitating everything that happens. (guest)

Response: Charmaine thanked John Nash for this important point.

Question: How will lessons from COVID-19 be incorporated into the Olmstead planning process? What can we keep? And how can we keep people moving into less restrictive environments, even given the virus? (guest)

Answer: CMS waived processes around the Pre-Admission Screening and Resident Review (PASRR) process which helps to prevent people with disabilities from going into nursing facilities (NFs). During the pandemic, CMS has waived this process to help move people into NFs more quickly. Discharges from the facilities to the community have been slower, with the idea that people are safer in institutions, so this is certainly an issue to discuss concerning Olmstead. 1915k waivers are emergency waivers that allow things like telehealth during the virus. Many other states are looking at making these types of waivers permanent for telehealth. Some flexibilities are at the federal level and some are at the state level, so looking at these policies for NC will be important as part of this process. (Kevin Martone, TAC)

Comment: I'm curious about group home oversight and accountability for inclusion, the ability for people to access the community, supports, services, and employment and move out. I have experienced frustrations from MCOs and providers about "who is responsible" to create standards for group homes and them not requiring people to go to a day program, as one example. (Member, Cherene Caraco, The Promise Resource Network)

Response: No response.

Comment: Money Follows the Person (MFP; Steve Strom) is excited to be part of this Olmstead project. We are supporting several projects to provide greater self-direction for individuals with disabilities, such as Rethinking Guardianship, development of a supported decision-making tool, generating more resources for individuals to utilize supported living in the Innovations waiver, and launching a demonstration project on utilizing technology during this pandemic. (guest) **Response:** Thank you for sharing these initiatives with the OPSA.

Next Steps

- Holly Riddle highlighted the next steps below:
 - \circ $\;$ Next meeting date will be chosen soon, and an invitation will go out
 - DHHS will work with TAC on how to approach plan development from here and how to get other experts involved in future meetings
 - o Suggestions for the vision/mission statement will be reviewed

Closing Remarks - OPSA Community Co-Chairs

• Betsy and Charmaine encouraged people to communicate via email to Holly.Riddle@dhhs.nc.gov if they have any additional thoughts after the meeting.