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November 8, 2021

Holly Riddle
North Carolina Olmstead Coordinator
North Carolina DHHS

The Technical Assistance Collaborative
c/o Jenn Ingle

By Email: ncolmstead@tacinc.org

Dear Ms. Riddle and Ms. Ingle

The North Carolina Council on Developmental Disabilities is grateful for the opportunity to comment on the draft North Carolina Olmstead Plan. The Council has forty members who are North Carolinians with intellectual and developmental disabilities (I/DD), family members, and state and agency leaders. The role of the Council is to engage in education, advocacy, capacity building and system change activities to ensure a coordinated system of community services and individualized supports for individuals with I/DD in North Carolina. Advocacy is defined for the Council to include “educating, advising, and informing” policy makers and leaders on matters to improve services for individuals with I/DD. Based on our federal law and regulations, then, it is a core responsibility of the Council to provide advocacy and feedback on the state’s draft Olmstead Plan.

The Council’s Designated State Agency is DHHS; nevertheless, the Council has an independent obligation separate from any connection with DHHS to advocate on behalf of the North Carolina I/DD community. This letter is written as part of the Council’s independent role and affirmative responsibility to provide advocacy and not based on any association with DHHS.

Accordingly, the Council spent considerable time reviewing the draft Olmstead Plan. It held a one and half hour virtual forum on the draft Olmstead Plan with the I/DD community with over 140 attendees. The Council also discussed the Olmstead Plan throughout our three-day annual meeting November 3rd, 4th, and 5th. A majority of Council members voted, with recusals from state agency members and one “no” vote, to submit comments on the draft Olmstead Plan.

The Council is grateful for your work as Olmstead Coordinator, the work of TAC, the work of the Olmstead Planning Stakeholder Advisory Committee, and the North Carolina Department of Health and Human Services.

Olmstead, as you know, is the most important United States Supreme Court decision for people with disabilities. It is often referred to as the *Brown v. Board of Education* decision for people with disabilities because the decision prohibited



people with disabilities from being unnecessarily segregated into institutions. *Olmstead* also held that unnecessarily segregating individuals with disabilities into institutions constitutes discrimination because it separates individuals from the typical activities in which others in the community engage and because it creates unwarranted assumptions that individuals in institutions are less valued than others in the community.

In *Olmstead*, the Supreme Court indicated states could create Olmstead Plans in order to comply with the integration mandate of the Americans with Disabilities Act. An Olmstead Plan is, in essence, a plan for how a state will ensure that its citizens and residents with disabilities will be ensured their inalienable rights to life, liberty, and the pursuit of happiness. Since it is now twenty-two years after the decision, the North Carolina I/DD community has had significant interest in the drafting of the Olmstead Plan and in the draft Plan.

After extensive review of the draft Olmstead Plan, the Council has concerns and comments it would like to share. These comments and concerns are as follows:

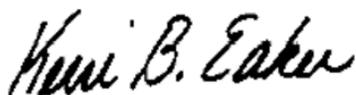
- (1) The Draft Olmstead Plan is a plan for only for two years. It ends in December 2023. This is not nearly enough time for the state to meet its obligations under Olmstead based on the current number of people on the state's Registry of Unmet Needs, the number of people in state institutions, and the work and investment needed to ensure people with disabilities can live full and meaningful lives in the community. Thus, the timetable needs to be extended. For Olmstead to be successfully implemented, North Carolina needs to have a five- to ten-year Olmstead Plan.
- (2) The Draft Olmstead Plan has specific targets and numbers of people who will receive services up through 2023. Even if all of these goals are accomplished, there would still be too many people with disabilities who were not able to realize their rights under *Olmstead*. There need to be goals, measurements and budgets for the additional years necessary to comply with *Olmstead*.
- (3) For the Olmstead Plan to be successful, there needs to be sufficient funding allocated to meet each of the goals and measurements.
- (4) The Olmstead Plan should show how the state will decrease funding in state institutions and increase funding in the community.
- (5) For Olmstead to be successful, there needs to be designated long-term ongoing staff with the authority necessary to work with the leadership of the Department of Health and Human Services (DHHS) and other state agency leaders to ensure adequate budgeting, implementation, and accountability. It should also include staff with lived experience with disabilities.
- (6) Olmstead applies to the work of entire state and not just to DHHS. The Council recommends that there be a multi-agency collaboration that includes all agencies with leadership responsibilities for Olmstead work that should be responsible for planning, budgeting and implementation of Olmstead.

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- (7) The state's Registry of Unmet Needs collects the names and information on individuals with I/DD who currently have unmet needs. This includes over 15,000 people who are waiting on the Innovations Waiver. The Olmstead Plan needs to address more specifically how all individuals with I/DD on the Registry of Unmet Needs will have their needs met through 1915(i) services, Innovations Waiver services, care coordination and other supports.
 - (8) The Council recognizes the gravity and importance of transitioning from (b)(3) services to 1915(i) services. The Olmstead Plan should thoroughly contemplate and include in partnership with DHHS the services provided through 1915(i) to ensure that there are not gaps for the individuals transitioning from (b)(3) services and to enable those who have unmet needs to have their needs met.
 - (9) The Olmstead Plan should include the provision of residential services in 1915(i) services.
 - (10) The Olmstead Plan work has included the development of a strategic state housing plan for people with disabilities. This is important work, particularly given the need for housing and the significant limitations in available affordable housing. There should be annual measurements and goals with specific funding allocations. Funding should include state funding, federal funding, and tax incentives.
 - (11) The Council agrees with the draft Olmstead Plan that there needs to be increased involvement, input, and inclusion of individuals with lived experience in all aspects of the development and implementation of the Olmstead Plan. The Council recommends stipends and/or compensation of individuals with lived experience in this work.
 - (12) There is a crisis in North Carolina with too few Direct Support Professionals (DSPs). This is due to the poor compensation for DSPs. The Olmstead Plan needs to include a plan for higher wages for DSPs, care coordinators, peers, and related employees in order to ensure the successful implementation of the Olmstead Plan. Also, there needs to be specific additional funding, services, and work done to address the needs of individuals receiving level 2 and 3 supported living services within the Innovations Waiver.
 - (13) The Council has repeatedly been told that there are systemic requirements and obligations (including a state employee living wage requirement) that cause direct support professionals and other employees in state institutions and other congregate settings to receive higher wages and benefits than direct support professionals and employees in the community. This imbalance needs to be corrected in the Olmstead Plan so that DSPs and employees providing equivalent services in the community receive equivalent wages.
 - (14) There needs to be more emphasis in the Plan for how individuals with lived experience and family members can be employed as family navigators, peer mentors, certified peer specialists, care coordinators and DSPs.

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- (15) The draft Olmstead Plan should include more measured goals for ensuring that substantially more people with disabilities are able to work in competitive integrated employment.
- (16) The Council also has significant concerns about the number of children with behavioral health, intellectual and developmental disabilities, traumatic brain injury, and other disabilities who are placed for treatment in costly PRTFs, including out-of-state PRTFs. The Olmstead Plan should have measurable goals, funding, and added community services and supports to ensure all children are able to live and thrive at home. Out-of-state PRTF placements must end, while in-state PRTF placements decrease and community-based children's behavioral health services expand.
- (17) Relatedly, the plan should include specific strategies for building the capacity of community-based providers to support individuals with IDD who have complex needs including medical and behavioral/mental health needs.
- (18) The Council has spent considerable time and effort on expanding resources and tools for increasing natural supports for individuals with I/DD. The Council looks forward to opportunities to continue to increasing these resources and tools as part of the Olmstead Plan development and implementation.
- (19) The Council has spent considerable time researching how the state could develop tools for matching roommates with I/DD or with direct support professionals. There are extraordinary tax benefits for a DSP who is a live-in caregiver for an individual with I/DD. The Council recommends expanding the housing options in the Olmstead Plan to include such tools and resources for matching roommates and live-in caregivers while also ensuring adequate background checks and other safety precautions to ensure a safe process.

The Council is grateful for the opportunity to comment on the draft Olmstead Plan. We look forward to continuing to engage with you on the development of the Olmstead Plan and its implementation. This is why our Council exists, and we look forward to working with you to ensure all individuals with intellectual and developmental disabilities in North Carolina can live full and meaningful lives in the community.

Sincerely,



Kerri Eaker
Council Chair



Talley Wells
Executive Director