

December 7, 2020
Board of Community Health
ATTN: DANISHA WILLIAMS
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To Whom it May Concern:

This letter is written as a joint effort by the partners of Georgia's developmental disabilities network and other disability and health organizations, including: the Georgia Council on Developmental Disabilities, the Georgia Advocacy Office, the Institute on Human Development and Disability, the Center for Leadership in Disability, the Statewide Independent Living Council of Georgia, The Arc Georgia, Georgia Options, Sangha Unity Network, the Center for Public Representation, and Georgians for a Healthy Future. We are writing to express our concerns regarding the current proposal for the Comprehensive Supports Waiver (COMP) Program renewal, and the New Options Waiver (NOW) Programs amendment, which were approved for public comment during the Department of Community Health's board meeting on November 12, 2020. Overall, we view the NOW and COMP programs as essential components to ensuring Georgians with developmental disabilities are fully included in community life, and we believe that innovative waiver proposals can have an immensely positive impact on the disability community when done with needs of people with disabilities and their families in mind. Unfortunately, we do not believe the current proposal as presented will result in a positive improvement to the lives of people impacted by the changes.

We would like to highlight the following proposed changes as our sources of primary concern:

1. Proposed 16 hour cap to Skilled Nursing Services
2. Proposed 6 hour cap to Additional Staffing services in Community Living Support settings
3. The elimination of Community Living Support services as an option for people who require more than a total of 12 combined daily hours of Community Living Support services and Additional Staffing services
4. The service definition change of Community Living Support services to include:
"Community Living Support services is available for individuals who spend periods of time throughout the day with unpaid unsupervised supports and services."

These caps and eligibility modifications will move Georgia further from providing people with developmental disabilities control and choice over where they live. This current proposal undercuts the creation of truly inclusive communities for Georgians with disabilities by effectively removing the option for people with more significant disabilities to live on their own. As was stated during the November 12th DCH board meeting, in order for people with more significant

disabilities to receive needed services, they will either have to rely on unpaid family caregivers, which is not always an option, particularly not long term, or they will be put in positions of having to leave their residence for a congregate setting such as a group home.

We submit the following three areas to support why the current proposal is problematic:

1. Home and Community Based Services Settings Rule

The current proposal is not aligned with the intent of the Home and Community Based Services (HCBS) Settings Rule and does not demonstrate principles set forth by the HCBS Settings Rule, particularly during a time in which the state is currently working to finalize their Statewide Transition Plan which is the blueprint for assisting state services in coming into compliance by 2023. The Home and Community Based Services (HCBS) Settings Rule was created in 2014 to ensure states were utilizing HCBS funds to support services that allowed people with disabilities to be truly integrated into their community and provided choice and autonomy for people with disabilities regarding how they spend their time. The HCBS Settings Rule specifically outlines that people receiving services should have choice regarding the services they receive and who provides those services. In addition, language is included in the Settings Rule to ensure that people with disabilities are able to choose their place of residence from multiple options, including nondisability specific options. The requirements in the Settings Rule were designed to ensure that people receiving HCBS funded services receive the same choice and autonomy over their lives as those who do not receive HCBS funded services, and we do not believe that the specific proposed changes in the current NOW/COMP amendment proposal we highlighted above appear consistent with the intent of the Settings Rule.

The proposed changes to the NOW/COMP waivers limit choice and autonomy of people receiving waiver services by imposing caps and limitations that would ultimately result in removal from their preferred choice of residence. This should be a concern for the state, particularly as CMS clearly stated to Georgia in its August 2018 letter regarding the status of its statewide transition plan that in order to get final approval, the state would be required to develop a plan to ensure there is capacity within the state to accommodate the choice of settings that are nondisability specific. Georgia fails to mention how it intends to provide people with choice of nondisability specific settings, and there was no mention of current capacity to accommodate choice or any plan stated to ensure adequate capacity in the future in Georgia's most recent iteration of its STP. The above proposed changes appear to be moving the state further from its target of providing choice of nondisability specific settings by actually eliminating services that would allow people with disabilities the choice of residing in their own homes.

2. Olmstead v. L.C. and the current Justice Department extension

We would also like to highlight that the proposed changes do not appear to align with the extension agreement that the state entered into with the Justice Department, which is partially in place to ensure the improvement of the quality and availability of services for

people with developmental disabilities living in the community. The state continues to make efforts to come into compliance; however, we believe the current proposal does not attempt to improve the quality and availability of current services, rather the proposal has the potential to significantly reduce the quality and availability of services for Georgians with the most significant disabilities. We believe there is a real risk for those Georgians with disabilities who were covered under the extension and were supported to move out of an institution and into the community, will be those most at risk for harm if these changes are approved.

3. Research-driven best practices

Finally, we would like to mention that the current proposal does not promote what the research regarding best practices in this area tells us, which is living in a setting of one's choice supports overall long-term health, increases opportunities to make choices, and demonstrates a consistent increase in quality of life outcomes. We have significant concerns about the potential health impacts the current proposed changes might have on people with developmental disabilities and would like to encourage proposals based on more on best practice research to ensure the well-being of the waiver participants. In addition, we have discovered during the COVID-19 pandemic additional health-safety reasons for why we do not want to encourage congregate living over independent-living options.

In addition to our above concerns, we would like to suggest additional language be considered during this renewal/amendment opportunity. The below are areas in which we believe the NOW/COMP proposals would benefit from additional language:

1. Include internet access and technology as allowable expenses in the NOW/COMP waiver. The state has recommended the addition of assistive technology and telehealth as service options in the current proposal, which we believe could be valuable, but these services rely on participants' ability to connect to the internet and having the technology needed to access the internet.
2. Include the following language for both telehealth and assistive technology services:
 - a. Both require robust, effective, person-centered planning assessment that includes ensuring the person receiving services is a meaningful part of the decision to use these supports, understands how to use them, and understands how to request changes if their needs/preferences change.
 - b. Remote services must be functionally equivalent to in-person services and that there is no disparity in outcomes correlated to method of service delivery.
 - c. Participants will not be steered towards remote service delivery, and participants choosing remote service delivery will have the option to change to in-person service delivery at any time.

3. Continue to allow family members to serve as paid support, as allowed under Appendix K. The shortage of direct care workers is not a crisis confined to the COVID-19 pandemic. Family members often are required to function as unpaid support, which in turn requires them to make difficult choices, including leaving the workforce, to provide care for loved ones that may put them and their families at financial risk. When the HCBS system cannot provide quality, reliable, consistent help those who are providing care should be compensated, and when family members are capable and willing and the participant desires it, family caregivers boost the capacity of the paid workforce to provide care for others.
4. Update the eligibility definitions of intellectual and developmental disabilities to reflect the most up-to-date clinical definition of both, both of which were modified in 2013, and have yet to be updated in the state's definition.

We would like to thank you for the opportunity to share our concerns and we look forward to the agency's response and to working together to create innovative waiver services that aim to improve the lives of Georgians with disabilities.

Sincerely,



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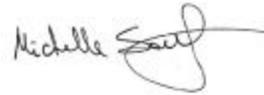
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