AUCD
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK

Senator Sherrod Brown
Senator Bob Casey
Senator Maggie Hassan
Representative Debbie Dingell
HCBScomments@aging.senate.gov

April 26, 2021

Re: Comments on HCBS Access Act (HAA) Discussion Draft and Home and Community Based Services Funding

Dear Senators Brown, Casey, Hassan, and Representative Dingell,

The Association of University Centers on Disabilities (AUCD) writes in response to the request for stakeholder comments on your discussion draft of the HCBS Access Act (HAA). We are aware that the timing of these comments also aligns with a unique opportunity to make progress around access to HCBS as proposed in the Administration's American Jobs Plan (AJP). AUCD supports and promotes a national network of university-based interdisciplinary programs with the mission to advance policies and practices that improve the health, education, and social and economic well-being of all people with developmental and other disabilities, their families, and their communities by supporting our members in research, education, health, and service activities that achieve our vision.

The importance of Home and Community Based Services: The *Home and Community Based Services Access Act (HAA)* draft, coupled with the increases in HCBS funding via the recent FMAP bump and the potential increase of $400 billion via the AJP, has the potential to forever change the Medicaid system for services and supports for people with disabilities. Removing the institutional bias by making HCBS services mandatory, rather than optional, and a state plan service with 100% FMAP removes the pressure for enrollment and eligibility caps and rate neutrality found in most waivers. It has the potential to fundamentally improve Medicaid services and supports to individuals with disabilities going forward and to promote an individualized, community based, integrated life that all people choose.

COVID and HCBS: The COVID-19 pandemic has highlighted many existing problems, from institutional bias to the need for improved, effective, and accessible case management, to simple lack of funding in Medicaid HCBS. While these problems have always existed, seeing them through a COVID-19 lens has magnified and exacerbated the issues to a place where change is not only necessary but imperative. Much research is being done on the relationship between COVID, people

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with disabilities, the Direct Support Professional (DSP) workforce, and necessary services and supports. The COVID-19 pandemic has provided additional new evidence demonstrating the urgent need for increased HCBS funding, flexible home and community based services and a stable and well-paid workforce. The necessity for HAA and for the AJP funding are demonstrated in the following studies, among others:

- Elevated COVID-19 Mortality Risk Among Recipients of Home and Community based Services: A case for prioritizing vaccination for this population from Disability Rights Education & Defense Fund (DREDF) – demonstrates the increased mortality risk for people with intellectual and developmental disabilities from COVID-19.
- State Actions to Sustain Medicaid Long-Term Services and Supports During COVID-19 from Kaiser Family Foundation (KFF) examining the policy action taken by states in Medicaid and particularly with Medicaid HCBS to adapt and improve services during COVID. Many of these can and should be adopted and expanded going forward.
- *The Direct Support Workforce and COVID-19 National Survey Report 2020: Initial Report* https://publications.ici.umn.edu/community-living/covid19-survey/overview
- *Direct Support Workforce and COVID-19 National Report: Six-month Follow-up* https://publications.ici.umn.edu/community-living/covid19-survey-6-month-followup/main -- updates the previous study six months later, into the pandemic. The final study included 8,846 participants from all 50 states.

Congregate and institutionalized settings and services: It has recently become clear through the discussion of the additional FMAP bumps to HCBS, as well as through the conversations about the HCBS funding increase in the American Jobs Plan, that there are those who believe that HCBS services and funding can apply to services and funding offered in congregate or institutional settings. That is not our understanding. Congress needs to be clear in any reference to HCBS funding and services that these are services NOT offered in such settings. To allow HCBS funding to pay for services offered in a congregate setting completely flips on its head the concept of community based, individualized, integrated services delivered to an individual based on their person-centered plan, wishes, and goals. Access to authentic home and community based services is both a civil rights imperative and a reflection of the evidence based best practice in supports that facilitate quality of life.

HCBS Settings Rule: Any definition of home and community based services certainly must comply with the settings definition and the criteria outlined in the Home and Community Based Services Regulation (and successor regulations). However, and additionally, we are concerned that the federal HCBS Regulation has not been implemented with fidelity by many states in relation to settings that provide employment and day services. Most states have determined that large facility-based, congregate day and work settings meet the requirements of the rule, even though they are not integrated into the broader community, possess isolating characteristics that impede HCBS participants from accessing or experiencing community to the same degree as individuals without disabilities who are not receiving Medicaid HCBS, and are not structured to foster individualized, integrated supports for HCBS recipients. One solution might be additional statutory language reinforcing the definition with reference to congregate vs. integrated settings, or limiting the list of specified services to include only those that are individualized and integrated.

Quality: Any legislation concerning HCBS services and funding should create effective quality improvement programs that build on existing structures to create robust state and federal oversight of HCBS programs. This structure should incorporate meaningful quality measures, mechanisms to develop new measures to fill gaps, and strategies to hold states accountable for meeting benchmarks. To be fully effective, the quality improvement structure must center the voices of beneficiaries in its design and implementation. Quality metrics cannot themselves provide sufficient oversight due to inevitable gaps in reporting and to the sheer diversity of services and needs that older adults and people with disabilities use. Therefore, the mechanisms must be supplemented with network adequacy provisions and an ombuds office. We also recognize that states running MLTSS programs will have a different quality measurement regulatory framework, so any HCBS quality improvement program must address both capitated managed care and fee-for-service delivery systems.

Direct Support Professionals: As demonstrated in the resources cited above, support and expansion of the DSP workforce continues to be an urgent need within HCBS. Without solutions to the staffing crisis, few of the other improvements to HCBS will be possible. DSPs provide the services and supports which enable people with disabilities to work, attend school, and otherwise be part of their communities. They are the linchpin of HCBS implementation.

Expansion of HCBS funding, services and authority provide an opportunity to build on the work that has been done by the AUCD network of UCEDDs, LENDs and IDDRCs, and others, to develop resources and solutions to train and raise the quality of DSP workforce.

A Technical Assistance Center could be written into legislation as a Project of National Significance at the Administration on Community Living (ACL) to build on the work that the AUCD network is already doing to provide critical training and advance the current workforce emphasis and expansion. Currently our centers offer the following:

- College of Direct Support (in close collaboration with NADSP, which originated as a pilot project of Institute for Community Inclusion (ICI) at the University of Minnesota
- College of Employment Services in collaboration with the Institute for Community Inclusion (ICI) at University of Massachusetts, Boston
- College of Personal Assistance and Caregiving in collaboration with the University of California, San Francisco
- College of Recovery and Community Inclusion in collaboration with Temple University

Additional UCEDDs doing work in the DSP space:

- The Boggs Center on Developmental Disabilities at Rutgers in New Jersey
- The Center for Human Development at the University of Alaska
- Institute for Human Development at University of Missouri, Kansas City
- North Dakota Center for People with Disabilities at Minot State University

Conflict free case management: Conflict free case management is essential to supporting people with disabilities to obtain person-centered plans and services that reflect their personalized goals and outcomes. It provides administrative and structural firewalls between eligibility and assessment, plan development and supports coordination, and services and supports. This is an HCBS requirement and improves person-centered planning. Currently it is not implemented consistently across states, so

language in any legislation must be clear and absolute, including clear qualification and requalification processes for case management/support coordination that includes no conflict of interest.

Health Care Authorities: When discussing the direct care workforce, we must be aware that this is a heavily unionized field. Even in right to work states, there are those suggesting home health care authorities may occupy those same positions, in place of unions. While we do not object, it is important to realize that this recognition cannot impact the rights of people with disabilities to select their own care worker. That individualized choice must be paramount. Further, nothing should deter the use of paid family/friends acting as direct care workers even if they do not have the professional, educational, or skills background. Again, this is about the choice of the individual for their caregiver. Finally, we must be mindful not to create or reinforce a system where executive structure at provider agency level is highly paid or top heavy.

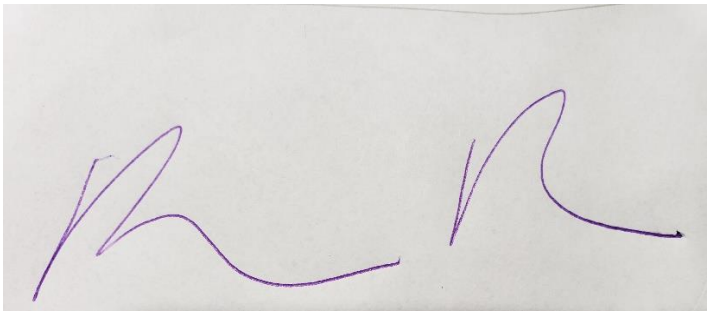
Family Care Givers: While talking about the importance of caregiving, we cannot forget the importance of family caregivers in the world of direct service for people with disabilities, and particularly people with intellectual and developmental disabilities. Most unpaid caregivers are women, more than half also work outside of the home, and nearly half report a financial impact from their caregiving responsibilities (NAC, AARP 2020). Family caregivers provide billions of dollars' worth of uncompensated care, without which disability service systems would collapse under the weight of need and costs (Swenson & Lakin, 2014). Fair wages for family care givers, and adequate respite and other family support services, are an essential component of HCBS, as are the goods and services that support that care.

Spousal Impoverishment and Money Follows the Person: Add to any legislation affecting HCBS services, whether through funding or HAA, language to make MFP and HCBS Spousal Impoverishment protections permanent, and require stratified data collection in the Money Follows the Person program.

Supported employment and integrated day services: Medicaid HCBS services currently provide states a way to support employment goals and outcomes as part of a waiver application. Currently, lack of adequate HCBS funding and services are barriers to invest in individualized, community-based employment support services to support competitive integrated employment for workers with disabilities. Any additional legislation and funding in this area should focus on the commitment by the federal government to competitive integrated employment as evidenced in the Workforce Innovation and Opportunity Act (WIOA). Given the federal priorities, states should be providing the most integrated service options based on evidence-based practices leading to competitive integrated employment, independent living, and community inclusion. Funding and legislation going forward must support this commitment.

Thank you for allowing us to share our thoughts on the HAA discussion draft and the funding of Medicaid HCBS services. We look forward to working with you as this legislation and funding move forward. Feel free to contact Rylin Rodgers (rrodgers@aucd.org) with questions or comments. We also are happy to connect you with network members doing work in each of these areas.

Sincerely,



Rylin Rodgers

Policy Director