



April 26, 2021

The Honorable Sherrod Brown
Senator
U.S. Senate
Washington, DC 20510

The Honorable Bob Casey
Senator
U.S. Senate
Washington, DC 20510

The Honorable Maggie Hassan
Senator
U.S. Senate
Washington, DC 20510

The Honorable Debbie Dingell
Representative
U.S. House of Representatives
Washington, DC 20515

Re: Opportunity to provide public comment on the Home and Community-Based Services Access Act

Submitted electronically via email to HCBScomments@aging.senate.gov

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

We write to you with appreciation and excitement regarding your discussion draft of the Home and Community-Based Services (HCBS) Access Act (hereafter referred to as “the Act” or “the HAA”) and to submit the following comments. Community Catalyst is a national, non-profit advocacy organization dedicated to quality, affordable health care for all. Since 1998, Community Catalyst has been working to build the consumer and community leadership required to transform the American health system. Our mission is to organize and sustain a powerful consumer voice to ensure that all individuals and communities can influence the local, state and national decisions that affect their health.

The Center for Consumer Engagement in Health Innovation at Community Catalyst is a hub devoted to teaching, learning and sharing knowledge to bring the consumer experience to the forefront of health. We work with state and local consumer health advocates to promote innovative, person-centered health care that uplifts the voices of communities. One key focus of our work is ensuring older adults, people with disabilities and individuals with complex health needs have access to the health care services and social supports they need. Since our inception, we have been working to improve Medicaid and Medicare for these populations and have seen how critical Medicaid Home and Community-Based Services are to individuals who need long-term care.

The COVID-19 public health emergency has additionally laid bare the critical need for individuals with complex or chronic health conditions to receive health care services at home or in their community to the greatest extent possible, to reduce the risk of illness, transmission and death. The pandemic has had a [devastating and disproportionate impact](#) on these populations, and particularly [disparate impacts on Black older adults](#), who are more likely to be [chronically ill](#) as a [result of racism](#) and age, and who are therefore more likely to become sick and die from the virus. Overall, the racial health disparities of the pandemic because of systemic racism have highlighted the need to reform the long-term care system in a way that truly promotes health and well-being. We believe the HAA has the potential to help make the long-term care system more equitable for those who need it the most.

We appreciate your support for The American Rescue Plan's significant step in improving access to Medicaid Home and Community Based Services by providing an additional 10 percentage point Federal Medical Assistance Percentage (FMAP) increase to states for one year, beginning on April 1, 2021, to be used to enhance, expand and strengthen access to HCBS. We hope you will also support the recently unveiled American Jobs Plan, which proposes to make an additional \$400 billion available to states for HCBS. We are excited by the potential of the HAA to build on these two policies if and when it becomes law.

Below are our comments on some of [the specific topics](#) your offices requested feedback on:

1. The minimum services and standards to be provided by state HCBS

Core Set of Home and Community-Based Services Quality Measures

We recommend the Act require annual state public reporting on a new set of HCBS quality measures showing how states are matching up to national benchmarks. To achieve this, we recommend the Act require the Secretary of Health and Human Services (HHS) to issue regulations on a core set and supplemental set of HCBS quality measures no later than one year after the date of enactment. Development of the measures should build on the comments HHS has already received on proposed HCBS Core and Supplemental Measure Sets, and use the many domains already specified in that process. In addition, *we recommend the Act require HHS, within three years of enactment, to issue regulations requiring all states to report on a mandatory set of those measures*, specifying how they meet or do not meet federal benchmarks also established in the regulations. To the extent practicable, the core measures should reflect the full array of HCBS services and HCBS recipients, and focus on consumer outcomes. The regulations should also allow states to retain the authority to add additional reported measures appropriate for their programs.

HCBS Quality Committee

We recommend that the HAA require HHS to establish a federal stakeholder committee to advise on selection, revision and development of new HCBS quality measures and benchmarks, and other steps to ensure quality of HCBS services. At least 51 percent of committee members should be individuals receiving or in need of HCBS, and representatives of advocacy organizations for members' rights, such as disability rights organizations, aging organizations, Protection and Advocacy organizations and Centers for Independent Living. The consumer committee members should represent the diversity of those

receiving HCBS nationwide across all demographics. To help ensure direct service workers have a strong voice in health care policy decision making that impacts them, ***we recommend the committee also be comprised of at least 25 percent HCBS direct service workers and at most 24 percent of other types of stakeholders involved in quality measurement, such as*** health plans, measure developers, measure steward organization, and relevant national associations of state officials. The quality committee should define and regularly update the HCBS quality measure set and act as an advisory body for other elements of the HCBS quality program. The Act should require HHS to provide staff support, training and other supports, such as transportation and stipends to the individual's participating.

We also recommend that the measure selection and development process engage not just the Agency for Healthcare Research and Quality as specified in the draft, and the stakeholder committee we specify above, but also the Administration for Community Living, the Centers for Medicare and Medicaid Services, and the Substance Abuse and Mental Health Services Administration. Lastly, the Act should also provide funding for the rapid development and testing of new HCBS quality measures to fill the many gaps in HCBS measurement as well as an enhanced administrative FMAP to cover state activities on quality measurement.

Data Collection and Stratification

We recommend that states be required to collect quantitative data on the quality of HCBS and other areas of HCBS in such a way to permit intersectional analysis as well as collect and report certain types of qualitative data. We support the Act's recognition of the need to collect data and support the renewed push that the COVID-19 pandemic has brought about to improve disaggregated data collection, verification and reporting, particularly in the areas of race, ethnicity, disability status, age, sex, sexual orientation, gender identity, race, ethnicity, primary language, rural/urban environment, and service setting. We recommend data be collected to permit intersectional analysis across multiple demographic categories, such as race and disability.

While disaggregated data is greatly needed, we also recommend that states provide more than just numerical data points. Therefore, we recommend the Act require states to provide qualitative information identifying why some demographics may not be receiving services at the same rate of other groups, and how the state will address these disparities. For example, communities of color have less access to secure housing and transportation, which limits the services they can receive in the home and community. States should describe creative strategies, like supportive housing or targeted case management, to improve access to services. The HAA should also require states to conduct needs assessments for various populations to establish baselines.

Elimination of Estate Recovery

We recommend that the Act eliminate estate recovery for HCBS. The Medicaid estate recovery policy, which permits states to recover long-term care costs from Medicaid enrollees by placing liens on their homes and seizing their assets, perpetuates intergenerational poverty and structural racism by significantly hampering the ability of Medicaid enrollees to pass on or transfer their wealth to their families. Recently, the Medicaid and CHIP Payment and Access Commission recommended that Congress make Medicaid estate recovery an option for states. We recommend that the Act preemptively take up this policy with regard to HCBS by updating Section 1396p of

the Social Security Act to eliminate estate recovery for HCBS.

Retroactive Coverage

We recommend the Act allow for 90-day retroactive coverage of HCBS. Right now, HCBS services are not retroactively reimbursable, while nursing home services are. Therefore, to create parity in access to long-term care no matter where an individual is receiving it, we recommend the Act amend Section 1396a(a)(34) of the Social Security Act to ensure that its requirements are applied to home and community-based services:

- 2. An HCBS infrastructure that supports workforce development and enables eligible Medicaid recipients to connect with qualified home care workers who fit the needs of older adults and people with disabilities**

Mandatory use of Enhanced FMAP to Support Workforce

We recommend the HAA require states to use the 100 percent FMAP to not only expand access to and service delivery of HCBS, but also to create a HCBS workforce infrastructure that increases compensation, training, and supports; guarantees workers the right to bargain collectively and ensures that HCBS rates are adequate to support the workforce needed to deliver services. Significant investments in the direct care workforce are critical to improving the quality of HCBS and ensuring that direct care jobs are high-quality jobs with family-sustaining wages and benefits. High turnover rates and worker shortages are directly connected to the quality of these jobs and, unless improved, there will not be the workforce necessary to ensure all those who require services are able to access them. Therefore, we believe the Act should provide for workforce development and support and that Section 7 should address issues such as wages, benefits, recruitment and retention.

Payments to Family Caregivers

To support HCBS workforce development, *we recommend the Act include policies to better allow family caregivers to be reimbursed by Medicaid for their services.*

State Direct Service Worker Registry

To help eligible Medicaid recipients connect with qualified home care workers, *we recommend the creation and funding of (perhaps by allowing states to receive 100% FMAP) state direct service worker registries* that are searchable by geographic area as well as skill-sets, languages spoken, and other factors that would be relevant to and important for HCBS recipients.

- 3. An HCBS infrastructure that provides supports to those navigating the long-term care systems**

HCBS Ombudsman Program

We recommend the Act create an independent HCBS Ombudsman program and require that states select a community-based, consumer-focused nonprofit to fill the Ombudsman role, similar to some of the Ombudsman programs established under the Affordable Care Act's Financial Alignment Initiative (FAI) through the Medicare-Medicaid Coordination Office. While some state Long-term Care (LTC) Ombudsman programs already serve individuals receiving HCBS, and others already have separate Ombudsman programs for home and community-based

long-term care, this type of program/service is not uniformly offered or required across all states. Similar to the LTC and FAI Ombudsman programs, we recommend the HCBS Ombudsman program be charged with serving as an advocate for individuals who are receiving HCBS, helping them resolve service complaints as well as other issues related to the health, welfare and their rights as individuals receiving HCBS. Unlike current Ombudsman programs, however, we also recommend that the HCBS Ombudsman be charged with helping individuals who are eligible for HCBS access these services, including by providing information and enrollment assistance, as well as by helping individuals transition off of HCBS waiting lists.

Specifically, the HAA should require states to designate an independent Ombudsman office (i.e., independent of the State Medicaid agency and any Medicaid managed care plans), with the dual purpose of 1) assisting individuals who are eligible for or enrolled in HCBS with accessing needed services, and 2) identifying, publicly reporting and working to address systemic problems with enrollment, eligibility, or access to services to the state. To facilitate prompt attention to systemic problems, we urge you to mandate quarterly public reports from the HCBS Ombudsman. Lastly, we recommend the HCBS Ombudsman program be funded through an enhanced administrative FMAP, based on current as well as potential or predicted enrollment in HCBS (i.e. taking into account individuals who are eligible for, but not currently enrolled in HCBS), so that it is properly resourced to meet the needs of all individuals who are eligible. Overall, having a dedicated Ombudsman program for HCBS will help ensure that HCBS throughout each state is meeting the needs of all individuals who are eligible.

4. The role of managed care in providing HCBS, in particular, issues such as network adequacy standards and ensuring that consumers can retain maximum autonomy to direct their care

Direct Testing of HCBS Provider Infrastructure

We recommend the Act require states and managed care companies to conduct active testing of access to HCBS providers. For example, states could use an external quality review organization, or similar entity, to conduct independent secret shopper surveys that test the accessibility and adequacy of the HCBS provider infrastructure. Another form of direct test could include creating a survey or interview to identify barriers to initial access of services (including for self-directed services). Additionally, states could review a representative sample of person-centered service plans and interview the persons served to identify if the services met their needs and if there were any problems fulfilling authorized services due to lack of access to providers.

For states that administer their HCBS programs through managed care, or decide to transition to a managed care delivery system for HCBS after the Act's passage, we recommend the Act require HHS to issue regulations establishing out-of-network provider access policies and strong continuity of care policies for individuals who wish to see an out-of-network provider, such as a

one-year continuity of care policy that some state FAIs use for their Medicare-Medicaid plan networks.¹

Lastly, we would like offer support for many of the provisions of the HAA as it is currently written. For example, we greatly appreciate the explicit inclusions of individuals with mental health disabilities, substance use disorders and other behavioral health conditions as populations who the Act specifically wants to ensure receive the HCBS services they need to live and thrive in their communities. We also appreciate the inclusion of peer support services as a type of HCBS. Finally, we strongly support the Act's explicit goal of eliminating health disparities based on race as well as the decision to provide states with 100 percent FMAP to provide HCBS to all who are eligible.

We thank you for drafting this transformational piece of legislation and look forward to working with you on making this bill a law. We believe the HAA can improve HCBS to those who currently rely on them as well as help expand the benefit's access to meet the needs of all individuals, no matter their level of support needs. Overall, we are strongly supportive of the HAA because it would help individuals with complex health needs, including older adults and individuals with disabilities, live the lives they choose.

Thank you for your consideration.

Respectfully submitted,

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¹ For example, California uses a one-year continuity of care period for Medicaid providers as well as a 6-month continuity of care period for Medicare providers. <https://www.cms.gov/files/document/camou.pdf>