

The Disability and Aging Collaborative

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

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

The undersigned member organizations of the Disability and Aging Collaborative (DAC) write with thanks and excitement around your discussion draft of the Home and Community Based Access Act (HAA).

The Disability and Aging Collaborative (DAC) is a coalition of approximately 40 national organizations working together to advance long-term services and supports policy at the federal level. Formed in 2009, the DAC was one of the first coordinated efforts to bring together disability and aging organizations. Members of DAC worked tirelessly over the past year advocating for dedicated funding to support Medicaid home- and community- based services (HCBS), because we understood that the optional status of these services under Federal Medicaid Law made them especially at risk.

We thank you for drafting this transformational piece of legislation, and DAC looks forward to working with you on making this bill a law. Broadly, we strongly support the HAA because it would provide access to people with disabilities to live the lives they choose, allow older adults to age in place, and include a clear lens for equity in both service delivery and the workforce that is providing those services. The DAC wants to ensure that HCBS remain available to those who currently rely on them and that access is expanded to meet the needs of all people with disabilities and aging adults, no matter their level of support needs. We want to highlight some areas where we advise modifications, as well as provide recommendations on the specific areas and issues for which you seek feedback.

Relationship between the HAA and the Medicaid Act:

The HAA is carefully drafted to ensure that the new service fits squarely within the structure of the Medicaid statute. Basic mandates of Medicaid, such as the requirements around statewideness, amount, duration, and scope, and due process that will apply to this benefit. This will allow the new benefit to be administered within the well-defined contours of the Medicaid program, and for CMS and states to draw on the fifty-year history of Medicaid to inform implementation of the new benefit.

We specifically agree with the decision to place the requirement for HCBS in a new section of 1902(a)(10)(D)(ii), after the current home health benefit. This placement makes sense. The home health benefit operates much like the new HCBS benefit will: just as home health is currently only mandated for those who are entitled to nursing facility services, HCBS will only be mandated for those who meet the new eligibility criteria. We further agree with including HCBS in the list of required services that states must provide to mandatory populations, as was done by amending 1902(a)(10)(A) to include HCBS, to ensure parity of HCBS with other required benefits. To ensure the greatest reach for this important policy change, Programs of All-Inclusive Care (PACE) also should be made a mandatory benefit in a subsequent new section so that all eligible Medicare beneficiaries may have access to this home and community-based model of care. At present, PACE is an optional Medicaid benefit offered in just 30 states.

Eligibility:

We are pleased that the eligibility components of the legislation represent the needs of both people with disabilities and aging adults. We suggest clarifying that individuals can be eligible with either 2 ADLs or 2 IADLs OR with one of each (1 ADL and 1 IADL).

Rate Setting:

A key reason that the HCBS service delivery system has not met the growing need for these services is because the reimbursement rates do not sufficiently reflect the full costs of services and are not keeping pace with needed investments. We recommend mechanisms for Federal oversight when it comes to approving state methodologies for funding services. We recommend setting a Federal floor for services to avoid variability across states. We also recommend including HCBS under the Equal Access Rule, which would require that Medicaid reimbursement rates are set to ensure timely access to services and to adequately compensate HCBS workers.

Workforce:

The direct care workforce is the cornerstone of HCBS, and this workforce has been undervalued for far too long. Ultimately, the interests of consumers and workers are inextricably linked—ensuring robust workforce supports is key to ensuring access to quality care. Without creating a durable workforce and workforce pipeline, it will not be possible to expand services to more people because there will not be enough individuals to provide services. The HAA must include infrastructure that provides for workforce development and support, including such issues as wages, benefits, recruitment and retention, as well as training and the ability for workers to collectively bargain.

Because Medicaid providers also fall under the jurisdiction of DOL, we strongly encourage Congress to incentivize and/or encourage formal processes and communications channels between DOL and HHS. This would ensure that providers can comply with new labor regulations that result in increased costs and interdepartmental outreach on apprenticeships and other programs. We recommend expanding pipeline programs by increasing training programs at IHE, career and tech education programs, Service Care Corps, etc. with low barriers to entry. We recommend increasing access to and utilization of self-direction, paid family caregivers, shared living, and other relationship-based models or models with longer retention and less reliance on paid staff. We recommend including the requirement and funding of national research and data collection, to take place at the state level, to better understand workforce issues and develop solutions. Congress should consider the National Core Indicators staff stability report as a model.

HCBS provider network adequacy

Ensuring that people who need a Medicaid HCBS provider can readily find an available provider is absolutely essential for any successful HCBS program. We also recognize that HCBS network adequacy oversight looks different under different care delivery systems. In Fee-for-Service, the State determines the provider rate and individuals have access to any participating provider. The legal and regulatory structure to enforce provider access relates to 1902(a)(30)(A) and the Access Rule. Under capitated managed care, the provider network is limited by a Managed Care Organization and oversight is regulated through the Medicaid managed care regulations. Both FFS and managed care are prevalent in state HCBS programs, so the HAA should address how to ensure provider availability and choice under both delivery systems.

Mandatory direct testing of provider networks. To the extent possible, we believe standards for network adequacy should be equivalent across delivery systems. Also, passive reporting of network adequacy has proven insufficient to identify problems in managed care. The HAA should direct CMS to mandate direct testing of provider networks in both managed care and

FFS delivery systems. The law should require all states and managed care plans to conduct active testing of their HCBS provider networks. For example, many states that use managed care contract with an external quality review organization, or similar entity, to conduct independent secret shopper surveys that test the accessibility and adequacy of the HCBS provider network throughout the HCBS service array and across geographically diverse regions in the state. 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). Or reviewing a representative sample of person-centered service plans to identify if the services met an individual's needs and if there were any problems fulfilling authorized services. Direct testing could also measure provider turnover for different types of HCBS or for different populations.

Equity

We appreciate the HAA's commitment to ensuring HCBS is received equitably across intersectional identities, including race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban environment, and service setting. We suggest that cognitive disabilities are included in the types of disabilities that are often siloed to include dementia and Alzheimer's disorders. (p. 3). The HAA clearly expresses the need to collect data on how services are used by different demographics and requires states to provide "a description of numerical goals to increase access to such services that have barriers to access." (p. 20). While disaggregated data is greatly needed, states should provide more than just numerical data points. States should provide qualitative information identifying why some demographics may not be receiving services at the same rate of other groups, and identify issues for additional advocacy at the state level and how the state will address these disparities. For example, communities of color have a disproportionate lack of access to secure housing and transportation, which limits the services they can receive in the home and community. The HAA should direct CMS to mandate that states create their own. States should describe creative strategies, like supportive housing or targeted case management, to improve access to services for older adults and people with disabilities experiencing disparities. The HAA should also require states to conduct needs assessments for various populations to establish baselines.

Individuals on tribal lands often face additional barriers accessing HCBS. Stakeholders should be consulted to identify how the HAA intersects with Indian Health Services and HCBS availability on tribal lands. Similarly, consideration should be made to ensure that U.S. Territories can implement HCBS through their Medicaid programs and receive any enhanced funding and supports available to states.

In the interest of equity, the HAA should change language that for individualized assessments, services are presumed to be rendered "in an individual's own home or community" so that it is

not interpreted as denying services to unhoused individuals (p. 13). Section 3(a)(4)(D) should include text confirming language access services for individuals with Limited English Proficiency, as well as accessibility for individuals with or visual, auditory, speech, or other communications impairments. (p. 14).

In addition to using state disability and aging agencies to provide outreach and education, states should also focus on alerting possible referral entities to programs often used by dually-eligible Medicare and Medicaid beneficiaries, including through dedicated outreach to hospital discharge planners, Area Agencies on Aging, senior centers and other community-based organizations. (p. 20). Dually eligible individuals are more likely to be people of color, and face worse health outcomes, particularly during the pandemic, compared to Medicare-only beneficiaries. Already, 49% of dually eligible individuals receive LTSS, while 60% have multiple chronic conditions. Thus, even more of this population is likely to be eligible for HCBS under the HAA. Thus, States should also highlight PACE, Medicaid-Medicare Plans (MMPs), Special Needs Plans (D-SNPs), and other managed care plans as part of their outreach to enroll dually eligible individuals in HCBS and divert them from institutional settings.

Section 6 Quality of Services

The section on HCBS quality 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 named in this section must be supplemented with network adequacy provisions and the ombuds office described elsewhere in this legislation. 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.

Data Stratification

The COVID-19 pandemic has reemphasized the longstanding structural inequities of our health systems. Moreover, the pandemic has exposed major holes in our data systems that prevent an effective way to even identify health disparities. Rightly, this failure has reenergized a push to improve data collection systems and build in the capabilities of those systems to collect, report, and verify data stratified by key demographic factors including by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban

environment, and service setting. Data should be collected to permit intersectional analysis across multiple demographic categories, such as race and disability.

We believe it should be the expectation that public health programs routinely incorporate the capacity to collect and report this data for all relevant health metrics, unless inappropriate for a particular measure. We recognize and support these efforts to prioritize demographic data collection and reporting, and urge the HAA bill sponsors to work in concert with other Congressional offices and federal organizations who are addressing these problems across public health and safety net programs, including Social Security, Medicare and Medicaid.

Goals for measuring HCBS Quality

Each state shall develop, recognize, implement, enforce, and publicly and periodically report on multi-faceted HCBS quality and accountability mechanisms. These mechanisms aim to achieve the objectives described in Section 2 of the HAA through at least the following components:

1. A HCBS core and supplemental quality measure set and benchmarks established at the federal level to assess performance at multiple levels, including state, health plan, and provider levels. The measure set should include robust, meaningful, and transparent quality metrics that are publicly reported annually and posted on each state's website, as well as mechanisms to address measure gaps
2. Quality advisory committees at both federal and state levels comprised of a majority of beneficiaries and their advocates, plus other stakeholders
3. Federal support of measure development
4. Federal technical assistance to states.

Establishing a federal HCBS Quality Committee

The Secretary of Health and Human Services, in collaboration with the Administration for Community Living, the Agency for Healthcare Research and Quality, the Centers for Medicare and Medicaid Services, the Substance Abuse and Mental Health Services Administration, and other agencies designated by the Secretary, shall establish a federal multi-stakeholder HCBS Quality Committee.

The committee shall consist of at least 51 percent individuals receiving or in need of Medicaid HCBS, and representatives of beneficiary rights organizations, disability rights organizations, aging organizations, Protection and Advocacy organizations and Centers for Independent Living. The beneficiaries must represent the diversity of those receiving HCBS across the nation, including diversity by race, ethnicity, gender, gender identity, sexual orientation, age, disability status, geography, and service setting. The remainder of the committee will include other

stakeholders involved in quality measurement, such as health plans, measure developers, measure steward organizations, and relevant national associations of state officials. The quality committee will define and regularly update the HCBS quality measure set and act as an advisory body for other elements of the HCBS quality program. HHS will provide staff support, training and other supports, such as transportation and stipends, to the individual beneficiaries participating.

Establishing a Core Set of Home and Community-Based Services Quality Measures

Not later than one year after the date of enactment, the Secretary of Health and Human Services shall issue regulations on a core set and supplemental set of home and community-based services quality measures. HHS has already received comments on a proposed HCBS Core and Supplemental Measure Sets, so the bill should reinforce that process. We support the domains chosen through that process.

Not later than 3 years after enactment, CMS shall issue regulations that require States to annually report on a mandatory base set of measures from the core set. Required measures should reflect, to the extent practicable, the full array of HCBS services and HCBS recipients. States retain the authority to add additional reported measures appropriate for their programs.

Core set parameters

The development of the HCBS core set should be the product of a collaboration between CMS, ACL, AHRQ, SAMHSA and key stakeholders, with a priority on beneficiary representation. The following elements should be part of legislative requirements for the Core and Supplemental Measure Set. CMS, in consultation with the multi-stakeholder HCBS Quality Committee will:

- select appropriate measures for each domain in the core measure set
- Set benchmarks for each core measure
- Determine the set of mandatory measures.
- Annually review and update the core measure set and mandatory measures.
- Within 2 years after enactment, require states to collect and report data on HCBS core measures disaggregated by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban environment, and service setting, unless the Quality Committee determines that such disaggregation would be inappropriate for a given measure.

Annual Public Reporting of HCBS core measure results

States will post at least annually on a public website an independent report on HCBS core measure performance. The State must arrange for an annual report produced by an

independent quality organization free of conflicts-of-interest with the state, such as an external quality review organization. States may not substantively revise the content of the annual report without evidence of error or omission. The report should include at least:

- Relative performance against the benchmarks established by CMS;
- Recent trends in the state’s HCBS measure performance, including at least the prior three years
- Stratified performance data, at least to the minimum standard set by the Quality Committee, and a written explanation of any measures that a state fails to report according to data stratification requirements or where there is evidence of flawed or incomplete demographic data.
- A narrative explaining significant health disparities identified in the data;
- A set of recommendations for specific corrective actions the state will take to ameliorate disparities or measures that fail to meet established benchmarks;
- A narrative responding to each recommendation from prior reports explaining actions taken to implement that recommendation and evaluating the effect of the actions taken.
- Non-duplication: To the extent that the above requirements can be accomplished as part of the external quality review process, the Secretary can deem EQR as fulfilling those requirements

Accountability and Oversight

- **Incentives and Corrective Action Plans based on performance**

Within one year of enactment, the HCBS quality committee, in consultation with federal agencies and subject matter experts, will explore how to establish appropriate quality improvement incentives and a system for creating and establishing corrective action plans for HCBS programs that do not consistently achieve quality benchmarks or repeatedly show patterns of problems identified through independent ombuds offices, government accountability offices, or other oversight entities.

 - Report of the committee’s findings will be posted on CMS website within 30 days of its completion;
 - Based on findings of this report, CMS will issue regulations within 18 months after the report is published to establish a system of incentives and corrective action plans to ensure state HCBS programs are meeting the objectives established under the purposes described in this section
- **State HCBS Quality Consumer Advisory Committees**

The committee shall consist of at least 51 percent individuals receiving or in need of Medicaid HCBS and representatives of beneficiary rights organizations, disability rights

organizations, aging organizations, Protection and Advocacy organizations and Centers for Independent Living. The beneficiaries must represent the diversity of those receiving HCBS in the state (including diversity by race/ethnicity, primary language, gender, gender identity, sexual orientation, age, disability status, geography, and service setting), and the state must consult with the leadership of the organizations listed in selecting beneficiaries. The remainder of the committee will include other stakeholders involved in quality measurement, such as health plans and providers. The state will provide staff support, training and other supports, such as transportation, interpretation and translation services, accessible materials and stipends to the individual beneficiaries participating.

Measure Development

The Secretary of Health and Human Services, in collaboration with the Administration for Community Living, the Agency for Healthcare Research and Quality, the Centers for Medicare and Medicaid Services, the Substance Abuse and Mental Health Services Administration, and other agencies designated by the Secretary, shall work with the HCBS Quality Committee named earlier in this section to:

- Review the HCBS core measure set, identify gaps in HCBS measurement, and prioritize measure concepts for development of new HCBS measures on an ongoing basis.
- Make recommendations for quality measure development to assess the adequacy of the HCBS workforce, including revisions in classification of HCBS workers.

Such sums as necessary shall be provided to the Secretary for rapid development and testing of HCBS quality measures based on the recommendations of the HBCS Quality Committee, in coordination with CMS, ACL, AHRQ, SAMSHA, DOL, and other relevant agencies.

Technical assistance with quality assessment and accountability programs

Such sums as necessary shall be provided to the Secretary to provide technical assistance to states, health plans, and providers, including assistance with:

- Meaningful use of HCBS measures in the core set to improve quality and outcomes.
- Initiatives to promote health equity, including the use of measures to address equity, including disaggregation by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban environment,

Enhanced FMAP for quality activities. States shall receive 100% FMAP for administrative activities related to adoption of HCBS quality measures, including consumer and other stakeholder engagement, data and quality infrastructure, expanding the sample size for beneficiary experience surveys such as HCBS CAHPS, NCI, NCI-AD and CQL-POMS, and public reporting of quality measures.

Independent HCBS Ombuds Program

While a robust HCBS core measure set can provide valuable information to guide quality improvement and strengthen health equity, quality measures alone will never be able to capture the full scope of care quality. A core quality measure set is necessarily limited and cannot cover every service type or subpopulation. Also, substantial data lags required for measure collection, verification, and analysis may lead to long delays before some problems even get identified.

For this reason, we recommend that the HAA mandate states to designate an independent ombuds office with the dual purpose to facilitate beneficiaries to resolve issues and access needed services; and to identify and report to the state -- and help address -- systemic problems with enrollment, eligibility, or access to services. The ombuds should uptake these duties with the goals of helping to ensure HCBS advances health equity, complies with the HCBS Settings Rule, increases the opportunity for HCBS beneficiaries to live in the least restrictive environment of their choice, reduce isolation and provide the opportunity for meaningfully engage in community activities e.g. volunteering, employment etc.

The MMCO's dual eligible financial alignment initiative created successful long term care ombuds programs charged with fulfilling both these purposes. In that initiative, the most effective ombuds programs function as an advocacy program, helping individuals understand their rights and providing assistance in resolving issues without infringing on an individual's right to appeal or file a grievance. Referral and education are also important functions of an ombuds program, but serving as an advocacy resource for individuals will ensure that individuals continue to bring problems to the attention of the program as they seek assistance. The program should be able to serve those receiving HCBS and those who are seeking such services.

An ombuds program for HCBS should be independent of the State Medicaid agency and any managed care plans. While MMCO allowed participating states to identify the best organization to serve as LTC ombuds for the financial alignment demonstrations, some of the most effective

programs used independent ombuds run by organizations outside of state government, as in New York and California. Similarly, New York's ICAN program operates as the ombuds for Medicaid managed care LTSS. North Carolina, after determining that an independent ombudsman would best achieve the goals of its ombuds program for the entirety of the managed care program, recently contracted with a consortium of legal services providers. While the ombuds programs need to provide confidential services and be able to work with the State agency, any managed care plans, providers, etc., they must not be so hampered by confidentiality and non-disclosure agreements that they cannot serve their function of reporting issues and transparency to the public about issues in the program, activities of the ombudsman, or other important function. The ombuds program should also be funded based on enrollment of HCBS so that it is properly resourced to meet the obligations of the program, and should include an enhanced administrative FMAP to fund its operations.

Finally, we recommend that the independent ombuds office post periodic quarterly reports summarizing its work and identifying any problems or repeated barriers to enrollment or accessing services it has encountered through its work with beneficiaries, including its recommendations to resolve these issues. The reports should include a mechanism for public disclosure to ensure transparency.

Summary

- Each state shall designate an HCBS ombuds office to assist beneficiaries directly and to identify and report systemic problems to state officials and the public. Each ombuds office must operate independently from the State Medicaid program and from any managed care plan. Each ombuds office has the following responsibilities:
 - Providing education regarding the rights and responsibilities of people participating in the HCBS program, including the right to file appeals or grievances and rights regarding services;
 - Providing confidential assistance and advocacy to help individuals resolve problems with accessing necessary services;
 - Referring and connecting people to resources to help resolve HCBS-related issues;
 - Identifying, investigating, and reporting to the state systemic problems involving beneficiaries, including problems with enrollment, eligibility, or access to services;
 - Working with community partners to gather information about potential problems or other issues with HCBS;

- Working with the State and other involved entities, such as managed care plans, to resolve identified problems;
- Creating periodic (quarterly) public reports on problems encountered, actions taken and recommendations made for systemic change;
- CMS shall provide each state with funds for the operation of an independent HCBS ombuds, using an enhanced administrative FMAP, and based on enrollment in HCBS.

Ensure Retroactive Coverage of HCBS

In contrast to Medicaid coverage for nursing home services, HCBS are not reimbursable, and therefore not available, until an official assessment is in place. The HAA should ensure HCBS services are made available immediately and reimbursable retroactively.

Make Spousal Impoverishment and Money Follows the Person Permanent.

Add new paragraphs to make MFP and HCBS Spousal Impoverishment protections permanent, and require stratified data collection in the Money Follows the Person program.

Eliminate Medicaid Estate Recovery

Today, states are required to seek recovery from the estates of deceased recipients for costs of nursing home services and HCBS for services rendered to recipients age 55 years or older. This policy not only perpetuates poverty and racial inequities, it deters individuals eligible for HCBS from seeking services placing them at higher risk for hospitalization and institutionalization and strains the economic security of families who step in to act as unpaid caregivers. The law should be amended to eliminate Medicaid estate claims.

The Disability and Aging Collaborative once again thanks you for your leadership in drafting the HCBS Access Act. We offer ourselves as a resource as you work through turning the discussion draft into legislation. If you have any questions, feel free to contact DAC co-chairs Howard Bedlin: Howard Bedlin Howard.Bedlin@ncoa.org or Nicole Jorwic: jorwic@thearc.org.

Sincerely,

Allies for Independence
American Association on Health and Disability
American Network of Community Options & Resources (ANCOR)
The Arc of the United States
Association of University Centers on Disabilities (AUCD)
Autism Society of America

Autism Society of America
Autistic Self Advocacy Network
Center for Public Representation
Community Catalyst
Easterseals
Justice in Aging
Lakeshore Foundation
Medicare Rights Center
National Academy of Elder Law Attorneys
National Adult Day Services Association (NADSA)
National Association for Home Care & Hospice
National Association of Councils on Developmental Disabilities
National Consumer Voice for Quality Long-Term Care
National Council on Aging
National Disability Rights Network (NDRN)
National Health Law Program
Service Employees International Union (SEIU)
TASH
Virginia Poverty Law Center