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AAHD - *Dedicated to better health for people with disabilities through health promotion and wellness*

LAKESHORE

April 26, 2021

Re: Medicaid Home-and-Community-Based Services Access Act – Discussion Draft Comments

To: HCBSComments@aging.senate.gov

The American Association on Health and Disability and the Lakeshore Foundation are delighted to see Congressional sponsorship of legislation to enhance access to Medicaid HCBS benefits, services, and supports, and greatly appreciate the opportunity to provide comments on the discussion draft.

The American Association on Health and Disability (AAHD) (www.aahd.us) is a national non-profit organization of public health professionals, both practitioners and academics, with a primary concern for persons with disabilities. The AAHD mission is to advance health promotion and wellness initiatives for persons with disabilities. AAHD is specifically dedicated to integrating public health and disability into the overall public health agenda.

The Lakeshore Foundation (www.lakeshore.org) mission is to enable people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation and research. Lakeshore is a U.S. Olympic and Paralympic Training Site; the UAB/Lakeshore Research Collaborative is a world-class research program in physical activity, health promotion and disability linking Lakeshore's programs with the University of Alabama, Birmingham's research expertise.

We were actively engaged as a member of the HCBS Access Act drafting teams for the Consortium for Citizens with Disabilities (CCD). Task Force on LTSS, and the Disability and Aging Collaborative (DAC). Our specialty niche was and is – performance and quality measurement. Since 2012, we have represented both the CCD LTSS Task Force (2012-2017) and the public health and disability experience in committees of the National Quality Forum.

Our comments are organized into two parts: **Section 6 – Quality of HCBS – Services and Supports - and Other Particular Areas of Concern, Focus, and Priority**

In addition to Quality Measures and Accountability, Other Particular Areas of AAHD and Lakeshore Foundation Concern, Focus, and Priority, include:

Discussion draft page 3, section 2 (5) – Eliminate silos and ensure that people with all kinds of multiple disabilities: **Suggested Insert: including persons with co-occurring disabilities and co-occurring disability and other chronic health conditions**…receive the services they need to live in their communities: **Suggested Insert: including, where appropriate, integrated general health, primary care, and behavioral health**

Discussion draft page 3 section 2 (7) – Ensure people with disabilities and aging adults have safe and meaningful options in the community.

Specific CCD LTSS suggestions regarding Self-Direction and Person-Centered Planning, and, persons with mental health disabilities and in need to mental health services.

Specific Disability and Aging Collaborative (DAC) suggestions regarding network adequacy, workforce, equity, and independent HCBS Ombuds Programs.

Section 6 – Quality of HCBS – Services and Supports

We cut and paste, below, the Disability and Aging Collaborative (DAC) comments on the proposed Section 6, Quality of HCBS - Services and Supports

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.

Thank you for the opportunity to comment. If you have any questions please contact Clarke Ross at clarkeross10@comcast.net.

Sincerely,

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Member, National Quality Forum (NQF) workgroup on Medicaid adult measures (December 2017-present), Medicaid-CHIP Scorecard Committee (October 2018-present) and Measure Sets and Measurement Systems TEP (June 2019-August 2020). Member, National Quality Forum (NQF) workgroup on persons dually eligible for Medicare and Medicaid (July 2012-July 2017) and NQF population health task force (2013-2014) http://www.qualityforum.org/) and NQF representative of the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports (http://www.c-c-d.org/). 2017 member, NQF MAP workgroup on Medicaid adult measures. 2016-2017 NQF duals workgroup liaison to the NQF clinician workgroup. 2015-2016 and 2014-2015 NQF duals workgroup liaison to the NQF PAC/LTC workgroup. Member, NQF Medicare Hospital Star Ratings Technical Expert Panel (June-November 2019 and September-October 2020). AAHD Representative to the CMS-AHIP-NQF Core Quality Measures Collaborative (2019-present). Member, ONC (Office of the National Coordinator for Health Information Technology) Health IT Policy Committee, Consumer Workgroup, March 2013-November 2015; Consumer Task Force, November 2015-April 2016. (http://www.healthit.gov/policy-researchers-implementers/federal-advisory-committees-facas/consumer-empowerment-workgroup). Member, SAMHSA Wellness Campaign National Steering Committee – January 2011-September 2014. (http://promoteacceptance.samhsa.gov/10by10/).

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