



American Association on Health & Disability

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



LAKESHORE

November 16, 2020

Re: Recommended Measure Set for Medicaid Funded Home-and-Community-Based Services (HCBS) – Response to CMS RFI

Submitted electronically to HCBSMeasuresRFI@cms.hhs.gov

Dear Colleagues:

The American Association on Health and Disability and the Lakeshore Foundation appreciate the opportunity to provide comments on this most important topic.

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.

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 are active members with the Disability and Aging Collaborative (DAC) and Consortium for Citizens with Disabilities (CCD) and were part of the suggested comments drafting team. Since

2012, we have been active members of a variety of committees of the National Quality Forum (NQF). Our AAHD and Lakeshore Foundation letter here further emphasizes several elements generally included in the DAC and CCD letters.

Overview

We appreciate that the Centers for Medicare and Medicaid Services have recognized the urgency and importance of creating a recommended set of HCBS measures. The HCBS core measure set will raise expectations for states and health plans to prioritize HCBS measurement. Moreover, it will help improve HCBS quality and may provide HCBS participants with data they can use to choose health plans (and eventually providers).

Still, we need much more. Given how critical HCBS is to people with disabilities and older adults, and given that HCBS now represents nearly one quarter of FFS Medicaid spending (with additional spending in managed care), a CMS recommended HCBS core measures is long overdue.¹ We urge CMS to move more swiftly with the goal of adopting a mandatory core set of HCBS measures. In the meantime, we ask that CMS continue to support the development and implementation of measures that help address some of the many gaps identified in this RFI, including especially *outcome* measures and a commitment to reporting measures stratified by key population demographics. Measures must be outcome-based and reflect the nature and values of HCBS.

The DAC, CCD, and AAHD-Lakeshore Fd comments focus on six elements: AAHD and Lakeshore have further emphasized several elements generally included in the DAC and CCD comments.

- 1) Report and make decisions with transparency and community input.**
- 2) Develop and use more measures that can be meaningfully implemented at the provider level and include an analysis of the Personal Outcome Measures (missing from the CMS RFI document).**
- 3) Strengthen the base measures related to community integration by focusing on “community inclusion” and “choice and control.”**
- 4) Stratify and cross-tabulate demographic data, including use of data stratification in the NQF domain on holistic health and functioning.**
- 5) Fill in key measure gaps - caregiver supports, workforce gaps, experience surveys precisely targeted to persons with mental illness, and the many consensus identified gaps and priorities in the reports of the National Quality Forum.**
- 6) Align core measures with elements of the CMS HCBS settings rule to streamline oversight and encourage states to take up core measures.**

Report and make decisions with transparency and community input

¹ MACPAC, FactSheet, Medicaid Home- and Community-Based Services: Characteristics and Spending of High-Cost Users, 1 (June 2018). See also, MACPAC, MACStats: Medicaid and CHIP Data Book, 57 (Dec. 2019).

- Post annual reports on CMS’s website based on state results from the base and extended measure sets. This follows the CMS Medicaid and CHIP core quality measures reporting process.
- Review and revise the recommended measure set annually, using a process that involves extensive engagement with HCBS participants and advocates. This process could follow the approach and composition used by the National Quality Forum with its committees on HCBS measures and measures for persons dually eligible for Medicare and Medicaid. Reliance on the work of the ACL (NIDILRR) funded University of Minnesota HCBS quality measures collaborative would be an essential and helpful analytical support.

Develop and use more measures that can be meaningfully implemented at the provider level.

- Provider level data is arguably the most readily actionable level for addressing care quality and would still provide a base for evaluating performance upstream at the plan or state level. Provider-level data also would more effectively inform ongoing monitoring of HCBS settings.
- Missing from the RFI document are the Council on Quality and Leadership (CQL) Personal Outcome Measures (POM), POM, and the CQL “Basic Assurances” are focused on organizational/provider assessments of the ability to deliver outcome-based services and supports that reflect the “nature,” “value,” and social determinants of HCBS.
- Many of the questions in the core measure set derive from HCBS CAHPS or NCI/NCI-AD. These survey tools are among the best we currently have to get a clear picture of the quality of HCBS services in Medicaid. However, few states have dedicated the resources to administer a large enough sample to give any kind of clear statistical picture of care quality at the provider level and can really only inform state or perhaps plan level performance.
- We realize that in many cases, provider level infrastructure may not be there. Given the positive reliance in the draft measure set on HCBS participant survey data – such as NCI and HCBS CAHPS – we encourage CMS to support states in using larger samples that enable measurement at the provider level, which is important for participants and for state oversight purposes.

Strengthen the base measures on community integration

Community inclusion, and choice and control over one’s life, are core to why HCBS are so important. The availability and quality of these services are essential to maximizing independence, autonomy, and quality of life for older people and people with disabilities. To know we are achieving meaningful community inclusion, we need to measure it.

Critical aspects of community inclusion overlap with other NQF domains like “choice and control” and “person-centered planning.” For example, the composite Community Inclusion measure from HCBS CAHPS is listed under Choice and Control. Even incorporating the

measures in those domains, however, the base measures in the proposed set are underrepresented and underdeveloped. We recommend shifting the following measures to this domain:

- HCBS CAHPS (this is current under Choice & Control)
 - Community Inclusion and Empowerment Composite Measure (Q 75, 77, 78, 79, 80, 81)
- NCI-AD (these are currently in the extended set)
 - NCI-AD-1: Percentage of people who are as active in their community as they would like to be
 - NCI-AD-2: Percentage of people who get to do things they enjoy outside of their home as much as they want to
 - NCI-AD-7: Percentage of people who are able to see or talk to their friends and family when they want to

We also recommend shifting the HCBS CAHPS Transportation to Medical Appointments Composite Measure from this domain, since it fits better in other domains.

We note that several measures in other domains are essential for assessing community inclusion, including CAHPS HCBS Q 56, 57: Choosing the Services That Matter to You Composite Measure, and NCI 50: The percentage of people who say they were able to choose the services they get as part of their service plan.

These changes would help align the measure set with requirements of the Medicaid HCBS Settings Rule, and draw from recommendations in a recent white paper² to focus on measuring the following outcomes:

- increased number of HCBS participants deciding what to do and with whom; increased number of HCBS participants having relationships with community members who are not paid to provide support or services; and
- increased number of HCBS participants having access to transportation or other support to access to community activities of choice.

While progress has been made in developing robust measures to gauge the extent and authenticity of community inclusion, we remain far from realizing strong measures that reflect the level of day-to-day choice and control an individual has over their life and daily schedule.

It is critical that CMS ensure that the HCBS core measures inform oversight and monitoring of important Medicaid HCBS regulatory requirements, such as the HCBS Settings Rule, person-centered planning, and the Medicaid managed care regulations. The purpose of the HCBS Settings Rule as set forth in the preamble is to ensure that all HCBS participants receive the full benefits of community living. Thus, a core measure set that aligns with and reinforces the HCBS Settings Rule will help streamline administrative oversight and increase public transparency. Several measures included in the base and extended sets directly align with elements of the HCBS settings rule measuring whether people have choice of roommates, ability to eat when

² HCBS Advocacy Coalition and the Community Living Policy Center at the Lurie Institute for Disability Policy at Brandeis University, "Tracking Progress and Success of Implementation of the HCBS Settings Rule: Potential Outcomes and Measurements" (available at <https://hcbśadvocacy.org/2020-outcomes-paper/>)

they want and host visitors at any time, control over their daily schedule, lockable doors, and more.³

Finally, we also think it is crucial that CMS identify and include a measure that gauges whether every individual has been offered the option of choosing a non-disability specific setting to receive their HCBS. This is a key element of the HCBS Settings Rule that is also a bedrock condition for successful community integration and could also be utilized by managed care to measure rebalancing efforts, one of the three required quality domains. Moreover, documenting the answer to this simple question would paint a clearer picture of provider capacity levels in the state and could help determine where to direct HCBS resources to bolster community supports. But availability of non-disability specific options is not a measure well reflected in the proposed core measure set.

Stratifying all data to elevate health equity as a quality priority

Include in every measure by emphasizing the importance of stratification and cross-tabulation of data by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, race, ethnicity, primary language, rural/urban environment, and service setting for all core measures. Provide states with technical support and, where possible, financial resources to expand stratification, including on all measures

Health equity should be at the forefront of any 2020 Medicaid quality measurement endeavor, particularly one involving older adults and people with disabilities. CMS’s national quality strategy, finalized in 2016, sets four “foundational principles” that guide the agency’s efforts to improve health and healthcare. The very first principle is to eliminate racial and ethnic disparities.⁴ The strategy identifies specific actions that could help states improve health equity, two of which relate directly to data collection:

- stratifying quality reporting by race, ethnicity, disability, and primary language to help identify health inequities; and
- building IT infrastructure that can readily incorporate such demographic data.⁵

The proposed HCBS core measure set in this RFI includes one domain for measures related to health equity, but that domain includes just a single measure (in the extended set) – an NCI-AD question on receiving services in their preferred language. The extended set also suggests that states should attempt to stratify data from “one or more measures (to be determined) by race, ethnicity, rural/urban, population type, dual-eligible status, etc.”⁶ Aside from this brief reference, the words “disparity” and “equity” appear nowhere else in the RFI main text or questions asked. This is a missed opportunity to fulfill CMS’s stated quality principles.

³ These include NCI 50, NCI 33 and 34, NCI 92, NCI-AD 16, NCI-AD 28-30, NCI-AD 32, and several composite measures from the HCBS CAHPS survey.

⁴ CMS, *CMS Quality Strategy 2016*, 5 (2016), <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Quality-Strategy.pdf>.

⁵ *Id.* at 10.

⁶ RFI, at 32.

Stratifying core quality data by key demographics deserves a much higher priority in this document and in Medicaid quality reporting more generally. To understand the complexities of disparate health care access for people with disabilities, policymakers need data broken down by key demographic groups for *all* reported measures, not just one. In accordance with the national quality strategy, CMS should provide states with technical assistance and enhanced administrative match to update computer systems to be able to report each core measure (including the adult and child sets) by key demographic groups. Measure stewards should build this capability into the measure development process. Data stratification must become a basic expectation for quality data reporting.

We recommend CMS specify that the state reporting on each core measure include stratified data by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language, rural/urban environment, and service setting. Where possible, such data should also be cross-tabulated, for example, showing the interaction between race and disability status. This data is essential to identify health inequities, target interventions at the communities or populations that need them most, and track progress in reducing or eliminating them.

We also recommend CMS provide states with technical assistance and enhanced administrative match to update computer systems to facilitate reporting each HCBS measure (as well as adult and child measures) by key demographic groups. Stratifying data is not nearly as challenging if it is included as a basic design expectation from the beginning.

Relatedly, we note that **the NQF domain on holistic health and functioning** would also benefit from a larger emphasis on data stratification. The RFI proposal includes just a handful of MLTSS measures in the extended measure set, including the proportion of HCBS enrollees who received a flu shot, who are screened for fall risk, and who have all-cause readmissions to hospitals within 30 days of discharge. These three measures would hardly capture the full range of holistic health quality for people using HCBS.

Policymakers, advocates, and enrollees would get a much clearer picture of the dimensions of holistic health for people using HCBS if states reported standard adult and child core measures stratified by disability and other key demographic characteristics. This would not require adding separate measures to the HCBS core measure set, but would help identify health disparities affecting people with disabilities and older adults related to common chronic conditions, behavioral health issues, BMI, and other health issues already included in the existing core measure sets (at least to the extent that HCBS users are already included in data reporting for the adult and child core sets).

We recommend that CMS keep the proposed measures related to exercise and included in this domain related to exercise, fall risk, and hospital discharge remain in the extended measure set.

Fill in key measure gaps

Fill in key measure gaps - caregiver supports, workforce gaps, experience surveys precisely for persons with mental illness, and the many consensus identified gaps and priorities in

the reports of the National Quality Forum. The DAC and CCD letters discuss some details related to caregiver supports and workforce gaps.

CMS should consult with ACL and collaborate with AHRQ, CDC, HRSA, and SAMHSA and financially invest in the development, testing, and piloting of actual quality measures to precisely address gaps identified in this letter and in gaps identified by others. CMS, ACL, and AHRQ have demonstrated this investment strategy and impact in the CAHPS HCBS Experience Survey and in the NCI/A-D instrument.

A major gap is experience surveys precisely targeted to persons with mental illness. NCI versions, POM, and CAHPS HCBS experience surveys include persons with mental illness but do not adequately address the uniqueness nor precisely report this targeted population. An instrument exists – **ECHO (Experience of Care and Health Outcomes) (for persons with mental illness)**. As documented by the NQF Medicaid adult core measures project, the NQF behavioral health committee, and the NQF-CQMC project (behavioral health committee) – ECHO is not NQF nor CQMC endorsed because of proprietary academic trademark ownership, no regular public updating process, and no public data collection, analysis, and reporting. This should be low-hanging fruit – an instrument that many stakeholders believe has value for a largely ignored population important to the Medicaid HCBS program that is “not” used and not regularly publicly updated and reported.

Some of the NQF project reported priorities include:

July 12, 2013 NQF to CMS Preliminary Findings report and February 28, 2014 NQF Interim Report to CMS (reaffirmed in 2015 & 2016) – 7 High Priority Measure Gaps

1. Goal-directed, person-centered care planning and implementation
2. Shared decision-making
3. Systems to coordinate healthcare with non-medical community resources and service providers
4. Beneficiary sense of control/autonomy/self-determination
5. Psychosocial needs
6. Community integration/inclusion and participation
7. Optimal functioning (e.g., improving when possible, maintaining, managing decline)

August 19, 2016 NQF MAP coordinating committee endorsed the NQF workgroup on persons dually eligible for Medicare and Medicaid 2 additional high priority measure gaps:

8. Home and Community-Based Services
9. Affordable and Effective Care

June 26, 2015 NQF to CMS draft report for public comment: Participants surveyed by NQF MAP recommended 4 additional high priority measure gaps (consistent with 2013-2014 gaps):

10. Beneficiary Experience
11. HCBS access and Rebalancing LTSS-transitions-care coordination

12. Health and general well-being (shift away from purely clinical outcomes)
13. Influence of social determinants of health

Align core measures with elements of the HCBS settings rule to streamline oversight and encourage states to take up core measures.

States already have to do ongoing monitoring of their HCBS settings, and aligning core measures with this other oversight regime could reduce administrative burden for states and encourage core measure uptake.

This approach would also more readily allow the HCBS core measures inform oversight and monitoring of important Medicaid HCBS regulatory requirements, such as the Settings Rule, person-centered planning, and the Medicaid managed care regulations.

The HCBS settings rule relationship is discussed in more depth in the above section on “community inclusion.”

Conclusion

Thank you again for moving the ball forward on HCBS quality measurement. We hope these recommendations will help inform your next steps in developing and strengthening the HCBS Core measure set.

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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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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