



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK

Comments on HCBS Core Measure RFI -Oct 14, 2020

Submitted electronically to HCBSMeasuresRFI@cms.hhs.gov

November 2, 2020.

Re: Request for Information: Recommended Measure Set for Medicaid-Funded Home-and-Community-Based-Services (HCBS)

Thank you for the opportunity to comment on this draft measure set. The Association of University Centers on Disabilities (AUCD) has long advocated for robust, meaningful, publicly reported home-and-community-based services (HCBS) quality measures in Medicaid. These measures are essential to ensure HCBS participants are receiving services that meet their needs, goals and preferences and help them thrive in the community.

AUCD supports and promotes a national network of university-based interdisciplinary programs. AUCD's mission is 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.

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 draft measure set will raise expectations for states and health plans to prioritize HCBS measurement. As importantly, it will help improve HCBS and will provide consumers data they can use to choose health plans (and eventually providers).

Yet, much more is needed. Given how critical HCBS is to people who use them, and given that HCBS now represents nearly one quarter of FFS Medicaid spending and additional spending in managed care, it is long past time for CMS to have mandatory quality measures in this arena. We urge CMS to move swiftly to adopt a mandatory core set of HCBS measures, and to continue to support development of *outcomes* measures, which are of most importance to consumers.

In the meantime, we recommend five critical changes:

- 1) Strengthening the base measures related community integration, which is critical to consumer quality of life but is underdeveloped in key measure set domains such as “community inclusion” and “choice and control.”
- 2) Focusing on health equity 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,

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- 3) 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.
- 4) Emphasizing the importance of caregiver supports by recommending states require care managers or health plans to assess the needs of family caregivers and address the needs identified. This is a promising practice that can temporarily fill in for the lack of measures on caregiver supports.
- 5) Prioritizing measure development on workforce gaps that result in low-quality care, and meanwhile, recommending states track and report ratios of support workers to participants and worker turnover.
- 6) Annual public disclosure of all state reporting results from the base and extended measure sets, and annual review and revision of the measure set involving extensive consumer and consumer advocate engagement. We also include several other process recommendations.

Following are our more detailed comments:

Strengthening 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. Critical aspects of community inclusion extend into other NQF domains like "choice and control" and "person-centered planning. Even incorporating the measures in those domains, however, the base measures in the proposed set are underrepresented and underdeveloped. We recommend adding the following measures to those currently recommended:

- 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 dropping 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.

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. In addition to incorporating all possible measures thereof from the extended set into the base set, we urge CMS to work with researchers to encourage more measure development in this area.

These changes would help align the measure set with requirements of the Medicaid HCBS Settings Rule, and are based on recommendations in a recent white paper¹ 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.

Stratifying all data to identify inequities

We recommend CMS specify that state reporting on each 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 and track progress in reducing or eliminating them. Health equity should be at the forefront of any Medicaid quality measurement endeavor, particularly one involving older adults and people with disabilities. Data stratification to help eliminate racial and ethnic disparities aligns with the first foundational principle of CMS's national quality strategy.²

The proposed measure set includes only a suggestion that states attempt to stratify data from one or more measures (to be determined), and a single measure of language access in the extended set, without any further discussion of health equity or disparities. This is a missed opportunity. 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.

Assessing caregiver needs

We call attention to the lack of any measures of caregiver supports in the draft measure set. This gap is particularly troubling, given the major role that 53 million adults play in providing unpaid LTSS to family and friends, and given that nearly one-quarter report caregiving is worsening their own health and one-fifth report caregiving is straining their finances.³

While measures are being developed, we recommend that CMS urge states to require care managers or health plans to conduct assessments of the physical, emotional, mental, social, and financial well-being needs of family caregivers or natural supports, and address the needs identified. This is a promising practice at least six states require of managed care plans.⁴

Addressing workforce gaps

¹ 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://hcbsadvocacy.org/2020-outcomes-paper/>)

² CMS Quality Strategy 2016. <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Quality-Strategy.pdf>

³ AARP and National Alliance for Caregiving. Caregiving in the United States 2020. Washington, DC: AARP. May 2020.

<https://doi.org/10.26419/ppi.00103.001>

⁴ AARP Public Policy Institute. Recognition of Family Caregivers in Managed Long-Term Services and Supports. April 2020. <https://www.aarp.org/content/dam/aarp/ppi/2020/04/recognition-of-family-caregivers.doi.10.26419-2Fppi.00090.001.pdf>

The proposed measures on workforce focus do not include any that address the low-quality care that results from workforce gaps, particularly in direct care. We urge CMS to support development of these measures, including measures of cultural competence (defined by the National Quality Forum as the degree to which the workforce delivers services aligned with the cultural background, values, and principles of the people who use HCBS).⁵ In the meantime, we urge CMS to recommend states track and report ratios of support workers to participants and staff turnover.

Improving the process, including reporting and transparency

- We recommend CMS **publicly disclose – at least annually -- all state reported results** from core and extended measures, similar to the way CMS currently posts annual reports of the adult and child core measure set results. Without that transparency, consumers will not be able to use quality data for plan or provider selection. To the extent that states use proprietary tools (such as National Core Indicators (NCI) or National Core Indicators – Aging and Disability (NCI-AD)) to collect core measure data, CMS should work to ensure data will be publicly available at no charge for quality measure reporting, with minimal data lag.
- We recommend that CMS **review and refine the HCBS measure set annually using a process that prioritizes the voices of consumers and consumer advocates** and how the measure set is working to improve service outcomes. The review process should include plain language materials accessible by HCBS users, including those with intellectual and developmental disabilities. Annual review would mirror the review of adult and child core measures, and is especially important given the ongoing measure development in HCBS, including the critical work at the University of Minnesota on outcomes measures. The review process must include plain language and translated materials accessible by users of HCBS themselves, including users with intellectual and developmental disabilities and individuals with limited English proficiency.
- We urge CMS to **prioritize “Importance of the Measure” and “Usability and Use”** as the most important criteria in measure selection. Overall, we agree with the five selection criteria: 1) Importance to Measure and Report; 2) Scientific Acceptability of the Measure Properties; 3) Feasibility; 4) Usability and Use; and 5) Related and Competing Measures. But we believe assessing the “importance of the measure” to people receiving HCBS and “usability” of the data by these consumers should be primary. While feasibility is important, this should not exclude measures that require the collection of survey-based person-reported outcome measures. While survey-based measures can be labor intensive and there are financial costs for states and/or health plans, these surveys are often the only way to assess meaningful HCBS outcomes. Given the current shortage of endorsed HCBS measures, we agree with CMS’s approach to allow temporary inclusion of promising measures that might not yet meet strict guidelines for scientific acceptability and feasibility.
- Given the positive reliance in the draft measure set on consumer survey data, we encourage CMS to **support states in using larger samples that enable measurement at the provider level**, which is important for consumers and for state oversight purposes. We also suggest CMS consider

⁵ National Quality Forum. Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement. September 2016.

http://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-Based_Services_to_Support_Community_Living_Addressing_Gaps_in_Performance_Measurement.aspx

recommending use of the Personal Outcome Measures® (POM), which typically focuses on the provider level, has been cross-walked against the Settings Rule, and is used by several states.

- We urge CMS to ensure that 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.

Thank you for again for moving forward on HCBS quality measurement. If you have any questions regarding these comments, please contact Rylin Rodgers, Director of Public Policy

Sincerely,

A handwritten signature in black ink, appearing to read "John Tschida". The signature is fluid and cursive, with a large initial "J" and "T".

John Tschida
Association of University Centers on Disabilities