



THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT
Lurie Institute for
Disability Policy

VIA ELECTRONIC TRANSMISSION

May 28, 2026

The Honorable Robert Kennedy, Jr.
Secretary of Health and Human Services
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

The Honorable Dr. Mehmet Oz
Administrator Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Re: CMS-2453-NC, Medicaid Program; 2028 Medicaid Home and Community-Based Services Quality Measure Set

Dear Dr. Oz:

Thank you for your continued work to implement the HCBS Quality Measure Set within the final “Ensuring Access to Medicaid Services” (Medicaid Access Rule) issued May 10, 2024. Origins of this work date back over a decade. In 2014-16, the Administration for Community Living (ACL) and CMS supported the development of a National Quality Forum (NQF) workgroup on HCBS quality which provided a framework for HCBS quality measures and catalyzed development of HCBS quality measures by CMS and other measure stewards. In July 2022, CMS released the first version of the HCBS measure set through State Medicaid Director letter #22-003. Building on this initial set, in April 2024, CMS updated the measure set and began requiring use within Money Follows the Person Program. The Medicaid Access Rule codified the measure set and outlined a process for updating and reporting on a mandatory set. This work has continued across multiple administrations. It is critically important and fills a longstanding need for use of standardized HCBS quality measures across states. This work will ensure that high quality services and supports are being provided to Medicaid HCBS

beneficiaries. It enhances transparency and will allow CMS, states, advocates, providers, and beneficiaries to work together to set benchmarks and improve quality. CMS has thoughtfully developed this measure set through numerous activities to gain broad-based public input and technical expertise from stakeholders.

Based on the “Request for Information” we provide the following suggestions and responses that we hope are helpful to CMS.

Should the 2028 HCBS Quality Measure Set be aligned with Mandatory Measures Required for Money Follows the Person?

- Yes, this will streamline measure activities and reporting for states, reducing burden and promoting harmonization. In the spirit of alignment and transparency, CMS should also publicly share the quality reporting from Money Follows the Person Program with stakeholders, including aging and disability advocates.

Should LTSS-1 and LTSS-2 be included in the 2028 HCBS Quality Measure Set? Should states be allowed to substitute FASI-1 and FASI-2?

- We agree that the quality and comprehensiveness of the person-centered planning process is a critically important measure concept.^{1,2} The extent to which these measures as currently specified achieved this, however, is questionable. They were originally developed as quality measures for use within Managed Long-Term Services and Supports (LTSS) programs. The core and supplemental elements that comprise the measures are overly medical in nature and could have unintended consequences in medicalizing the person-centered planning process. We believe that additional stakeholder engagement and input is needed to re-specify the measures.
- If CMS includes LTSS-1 and LTSS-2 in the mandatory or optional set, we ask CMS to explore the feasibility of linkages with T-MSIS reporting and making data available to outside researchers. This could promote additional research, such as the extent to which these measures may be associated with other outcomes, such as utilization of services, avoidable hospitalizations and emergency department visits.
- We strongly disagree with allowing states to substitute Functional Assessment Standardized Items (FASI): FASI-1 and FASI-2. These measures are similarly limited, focused on function, and do not include other key elements of person-centered assessment and planning, such as individualized, person-centered goals and desires. To our knowledge, these measures are also not widely used.

Is Stratification Feasible? What Characteristics Should Be Required for Stratification?

- Stratification of LTSS-1, LTSS-2, LTSS-6, LTSS-7, and LTSS-8 by geography (rural status) is very feasible and low burden for states. We agree that it is preferable for CMS to calculate these measures and do the stratification to ensure more standardization. For example, one concern we have is the possibility of differences in how states might define HCBS/LTSS (denominator), which would make comparisons between states challenging. CMS has developed more standardized methods for this within T-MSIS data. However, we believe that CMS should only do this for states with high-quality HCBS/LTSS data. In recent reports, CMS has flagged many states as having “high concern” HCBS/LTSS data with T-MSIS reporting.³ Using HCBS data that has known high levels of concern, severely compromises reliability and validity, and will produce poor quality measures. For states with high concern HCBS data, CMS should require corrective action plans to improve the quality of their HCBS/LTSS data reporting with T-MSIS to acceptable levels.
- It would similarly be highly feasible and low burden to stratify by other characteristics, including disability subpopulation and race/ethnicity. One suggestion, particularly for LTSS-6-8, is for CMS to consider aligning stratification for these measures on the same characteristics as those within the CMS/Mathematica Users and Expenditures for HCBS Reports.⁴ More specifically, we suggest the following categories: 1) Older adults (ages 65 and older); 2) People under 65 with potentially disabling conditions; 3) People with autism spectrum disorder, intellectual disabilities, or other developmental disabilities; and 4) People with mental health conditions or substance use disorders. These measures (LTSS-6-8) conceptually get at “rebalancing” and transitions into and out of institutional settings. We acknowledge that there are limitations in categorization of some subpopulations based on claims data. For example, work we have done indicates that people with intellectual and developmental disabilities will likely be under identified. However, there is considerable literature indicating access to HCBS and drivers of institutionalization differ for certain subpopulations.⁵⁻⁷ Therefore, this stratification would help CMS and states tailor more targeted interventions to improve quality and outcomes.
- Similarly, we believe stratification by race/ethnicity is also critically important to drive targeted quality improvement. However, we are very concerned about the quality of

race/ethnicity data within T-MSIS and methods used by CMS to impute race/ethnicity.⁸

We suggest stratification for states with high-quality race/ethnicity data, while simultaneously requiring states to develop corrective action plans to improve the collection and reporting of high-quality race/ethnicity data within T-MSIS.

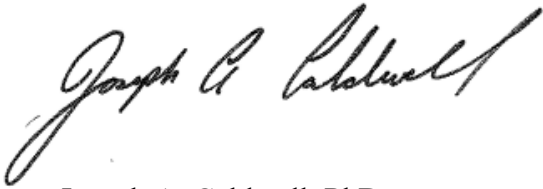
Should Other Voluntary Measures Be Part of the Mandatory Core Set?

- We believe CMS should include additional quality measures from consumer experience surveys (NCI-IDD, NCI-AD, and HCBS CHAPS). Since states will already be conducting these surveys for other measures, this would likely add little to no additional burden. One critical area we view as glaringly missing in the 2028 HCBS Mandatory Core Set is the adequacy of the direct care workforce. There is a well-documented direct care workforce crisis where many individuals and providers are facing challenges recruiting and retaining high quality workers.⁹⁻¹¹ While there are larger systemic issues impacting the crisis, there is a clear role for states. Many states are actively engaged in a variety of strategies and activities to improve the workforce.¹²⁻¹⁴ Moreover, there is some literature indicating that staff turnover is associated with negative outcomes for beneficiaries including risks of abuse, neglect, and preventable hospitalizations.¹⁵ This domain of quality is directly tied to the purpose of the Medicaid Access Rule; it also supports the priorities of CMS and the Administration for Community Living (ACL). Within NCI-IDD, NCI-AD, and HCBS CHAPS are numerous existing measures that assess the adequacy of the workforce. More specifically, within NCI-IDD and NCI-AD, we recommend considering measures that assess a) whether staff turnover too frequently and b) whether staff treat consumers with respect. We have used these measures in our work exploring outcomes of self-direction. The staff turnover measure has a high degree of variability and room for improvement, perhaps making it the most ideal measure for inclusion in the mandatory set at this time. Inclusion of consumer-reported measures on the adequacy of the direct care workforce would fill a critical gap supported by the literature and assist CMS and states in targeted actions to improve quality and ensure access to HCBS.

Thank you for the opportunity to respond to the Request for Information and provide suggestions. We applaud the dedicated work of CMS to develop the measure set and meet the timeline for implementation in the Medicaid Access Rule. We are happy to answer questions and

provide additional information. We look forward to continued partnership to advance this important work.

Respectfully Yours,

A handwritten signature in black ink, reading "Joseph A. Caldwell". The signature is written in a cursive style with a large, sweeping initial "J".

Joseph A. Caldwell, PhD
Senior Scientist
Director Community Living Policy Center

References

1. Daniels, E., Caldwell, J., & Stober, K. (2026). Associations of Person-Centered Planning and service coordination with health outcomes of adults with developmental disabilities. *Journal of Intellectual Disability Research: JIDR*. Advance Online Publication. <https://doi.org/10.1111/jir.70109,%20Advance%20Online%20Publication>
2. Chong, N., Caldwell, J., Kaye, H. S., & Mitra, M. (2024). Outcomes of Person-Centered Planning in Medicaid Home- and Community-Based Services. *The Gerontologist*, 64(6), gnae017. <https://doi.org/10.1093/geront/gnae017>
3. Larsen, A., Stepanczuk, C., & Wysocki, A. (2025). *Analysis of data quality in the Transformed Medicaid Statistical Information System Analytic Files for identifying Medicaid Home and Community-Based Services and institutional Long- Term Services and Supports, 2023*. Mathematica for Centers for Medicare and Medicaid (CMS). <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-users-taf-method-2023.pdf>
4. Carpenter, A., Stepanczuk, C., Murray, C., & Wysocki, A. (2025). *Trends in users and expenditures for Home and Community-Based Services as a share of total Medicaid Long-Term Services and Supports users and expenditures, 2023*. Mathematica for Centers for Medicare and Medicaid (CMS). <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2023.pdf>
5. Levine, A. A., Cole, M. B., Michals, A. L., Wang, N., & Rubenstein, E. (2025). Inequities in Medicaid Home- and Community-Based Services waiver enrollment among people with intellectual and/or developmental disabilities: A nationwide claims-based analysis. *Disability and Health Journal*, 18(3S), 101676. <https://doi.org/10.1016/j.dhjo.2024.101676>
6. Jenkins Morales, M., & Robert, S. A. (2020). The effects of housing cost burden and housing tenure on moves to a nursing home among low- and moderate-income older adults. *The Gerontologist*, 60(8), 1485–1494. <https://doi.org/10.1093/geront/gnaa052>
7. Fabius, C. D., Thomas, K. S., Zhang, T., Ogarek, J., & Shireman, T. I. (2018). Racial disparities in Medicaid Home and Community-Based Service utilization and expenditures among persons with multiple sclerosis. *BMC Health Services Research*, 18(1), 773. <https://doi.org/10.1186/s12913-018-3584-x>
8. Bixby, L., Daniels, E., & Caldwell, J. (2025). *The quality of race and ethnicity data among Medicaid beneficiaries receiving Long- Term Services and Supports* [Research Brief]. Lurie Institute for Disability Policy, Brandeis University. <https://heller.brandeis.edu/community-living-policy/research-policy/pdfs/briefs/quality-of-race-and-ethnicity-data-among-medicaid-beneficiaries-receiving-ltss.pdf>
9. *NCI state of the workforce for intellectual and developmental disabilities 2024 survey report*. (2025). National Core Indicators Intellectual and Developmental Disabilities. https://idd.nationalcoreindicators.org/wp-content/uploads/2025/12/2024-NCI-IDD-SoTW_Final-Tagged.pdf
10. *The state of America's direct support workforce crisis 2024*. (2024). American Network of Community Options and Resources (ANCOR). <https://www.ancor.org/wp-content/uploads/2024/12/The-State-of-Americas-Direct-Support-Workforce-Crisis-2024.pdf>
11. *National Core Indicators aging and disabilities state of the workforce in 2023 survey report*. (2024). National Core Indicators Aging and Disabilities. https://nci-ad.org/upload/reports/2023_NCI-AD_SoTW_FINAL_4_14_25.pdf
12. *Direct care workforce strategies center*. (2026, April 14). Administration for Community Living | ACL. <https://acl.gov/DCWcenter>

13. *Strengthening the direct care workforce*. (2025, January 15). Administration for Community Living | ACL. <http://acl.gov/programs/direct-care-workforce>
14. Tyler, D., Hunter, M., Porter, K., Horvath, M., & Suarez, G. (2024). *State efforts to improve direct care workforce wages: State case studies report*. RTI International for the Office of the Assistant Secretary for Planning and Evaluation (ASPE). <https://aspe.hhs.gov/sites/default/files/documents/ba806f15767b42593752744aab3e17ba/dcw-wages-state-case-studies.pdf>
15. Friedman, C. (2021). The impact of direct support professional turnover on the health and safety of people with intellectual and developmental disabilities. *Inclusion*, 9(1), 63–73. <https://doi.org/10.1352/2326-6988-9.1.63>