C+TAC
COALITION TO TRANSFORM ADVANCED CARE

May 27, 2026

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-4201-P
P.O. Box 8013
Baltimore, MD 21244

Re: Medicaid Program; 2028 Medicaid Home and Community-Based Services Quality Measure Set

Submitted electronically via www.regulations.gov

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to provide comments on these measures regarding their effect on those living with serious illness and their caregivers.

C-TAC is a national, non-partisan, not-for-profit coalition dedicated to ensuring that all those living with serious illness, especially the sickest and most vulnerable, receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. C-TAC comprises 200 national and regional organizations, including patient and consumer advocacy groups, practitioners, health plans, faith-based and community organizations, and others who share a common vision of improving care for serious illness in the U.S.

C-TAC defines serious illness as a health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life or excessively strains their family caregivers. This definition has been widely adopted, including by the National Committee for Quality Assurance (NCQA) and the National Quality Forum (NQF). Serious illness also differs by geography. People living in rural areas are older, sicker, and lack access to the full range of health care, and we advocate for improved care for any with less access to it.

Here are our comments:

Overall perspective

C-TAC strongly supports CMS's goal of establishing a standardized, evidence-informed HCBS Quality Measure Set that can be used across states to drive improvement, monitor equity, and promote accountability for outcomes that matter to beneficiaries. The proposed measure set appropriately emphasizes person-centered planning, choice, community participation, safety,

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transportation, and successful transitions from institutional settings back to the community. These domains are critically important for people with serious illness whose needs often span medical, functional, psychosocial, and spiritual dimensions and whose goals frequently prioritize remaining at home and avoiding unwanted, burdensome care.

At the same time, C-TAC urges CMS to ensure that the final measure set fully reflects the experiences of people living with serious illness and their caregivers. For them, quality is measured not only by the presence of services, but by whether care is coordinated across settings, aligned with the individual's goals, responsive to symptom burden, and inclusive of caregiver support. We encourage CMS to use the HCBS Quality Measure Set as a platform for more systematic attention to serious illness needs in Medicaid HCBS, including the ways that HCBS interact with palliative care, hospice, and other home and community-based services.

Importance of person-centered planning for serious illness

C-TAC supports CMS's proposal to retain LTSS-1 (Comprehensive Assessment and Update) and LTSS-2 (Comprehensive Person-Centered Plan and Update) as mandatory measures. For people living with serious illness, a high-quality comprehensive assessment and person-centered plan are fundamental to ensuring that HCBS address what matters most to the individual and family. In fact, that is an essential part of palliative care where an initial comprehensive assessment then prompts interventions to address identified needs. These measures create important accountability for whether states and HCBS programs are systematically assessing needs, preferences, and risks and translating them into actionable plans.

We recommend CMS, however, to clarify that for seriously ill beneficiaries, comprehensive assessment and planning should explicitly include: the individual's goals and priorities for care and daily life; symptom burden and functional limitations; family caregiver capacity and burden; cultural, spiritual, and communication preferences; and anticipated disease trajectory where clinically appropriate. Person-centered plans should document how HCBS will support the individual's goals, including staying at home, managing distressing symptoms, reducing avoidable crises, and supporting family caregivers. Plans should also specify how HCBS will coordinate with primary care, specialty care, and palliative care where involved.

C-TAC also supports allowing states to use HEDIS-equivalent or FASI-based alternatives to LTSS-1 and LTSS-2 where appropriate, so long as these alternatives maintain a strong focus on serious-illness-relevant content (such as goals of care, caregiver needs, and functional decline) and are not implemented in ways that dilute accountability for comprehensive, person-centered planning.

Measures most salient to serious illness

Among the proposed mandatory measures, several are particularly salient for people living with serious illness and their caregivers:

- HCBS CAHPS measures related to personal safety, respect, and choosing services. Seriously ill individuals are often highly dependent on paid caregivers and vulnerable to abuse,

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neglect, disrespect, or loss of autonomy. These measures help illuminate whether HCBS are delivered in ways that preserve dignity, safety, and a sense of control.

- NCI-AD and NCI-IDD measures related to community participation and service plan alignment with preferences and choices. For many people with serious illness, being as active in their community as they wish, within their limitations, is a central goal. These measures can highlight when HCBS are not adequately supporting community engagement.

- LTSS-6, LTSS-7, and LTSS-8, which focus on admissions to facilities, minimizing facility length of stay, and successful transitions after long-term facility stays. People with serious illness are at high risk for avoidable facility use and prolonged institutional stays. These measures are important indicators of whether states and plans are using HCBS to support rebalancing toward the community and to prevent or shorten institutional placements.

- POM measures related to freedom from abuse and neglect, choice of services, participation in community life, and achievement of personal goals. For seriously ill beneficiaries, these are fundamental outcomes that should be visible in quality reporting, not treated as peripheral.

We encourage CMS to maintain and, where feasible, strengthen these measures in the final 2028 HCBS Quality Measure Set. We also encourage technical assistance to help states interpret results specifically for populations with serious illness and high functional impairment, including dual-eligible beneficiaries, people receiving home-based palliative care, and individuals with dementia.

Caregiver experience and support

Family caregivers are essential partners in care for people living with serious illness and are often the primary coordinators of HCBS. Yet caregivers frequently lack training, respite, emotional support, and clear points of contact when problems arise. While the current HCBS measure set includes important beneficiary experience measures, there remains a gap in systematically capturing caregiver experience and support needs within Medicaid HCBS programs.

C-TAC encourages CMS to address the importance of caregiver-focused quality measurement and to prioritize the development and testing of HCBS measures that capture caregiver experience, burden, and access to support (for example, respite, training in symptom management, and assistance navigating HCBS and related benefits). In the interim, CMS can encourage states to use existing survey modules or supplemental questions, where available and appropriate, to gather information about caregiver experience as part of their HCBS quality strategies.

Stratification and serious illness

C-TAC supports CMS's proposed approach to stratification as an initial step, including geographic stratification for LTSS-1, LTSS-2, LTSS-6, LTSS-7, and LTSS-8. We note that people

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with serious illness from communities of color, rural areas, and low-income households often experience compounded barriers to accessing HCBS, including workforce shortages, limited provider choice, and lack of transportation. Stratified reporting is essential to uncover and address these disparities.

We encourage CMS, over time, to explore additional stratification or analytic approaches that can better capture serious-illness-related disparities, such as stratification by dual-eligibility status, disability category, and indicators of high clinical complexity or functional impairment. CMS should also support states in using stratified HCBS quality data in conjunction with other quality programs (for example, managed care quality strategies, hospital and nursing facility quality programs, and palliative care initiatives) to design targeted interventions for seriously ill populations.

Implementation and burden considerations

C-TAC recognizes that states face significant operational and workforce challenges in implementing HCBS quality measurement, particularly for measures requiring assessment and case management data or participant-reported surveys. We support CMS's efforts to streamline reporting, leverage existing data sources, and phase in stratification requirements over time. At the same time, it is critical that efforts to reduce burden do not weaken accountability for the experiences of people with serious illness and their caregivers.

We encourage CMS to provide targeted technical assistance, model language, and examples to help states embed serious-illness considerations into assessments, person-centered planning, survey administration, and quality improvement activities. This could include guidance on identifying beneficiaries with serious illness within HCBS populations; integrating HCBS measures into palliative care and serious-illness initiatives; and using HCBS quality data to monitor access to home-based palliative care and other community-based services that are particularly important for those living with serious illness.

Recommendations

- Retain LTSS-1 and LTSS-2 as mandatory measures and clarify that for people with serious illness, comprehensive assessment and planning should explicitly address goals of care, symptom burden, caregiver needs, cultural and spiritual preferences, and coordination with palliative care where appropriate.
- Maintain and strengthen measures related to safety, respect, choice of services, community participation, and successful transitions from facilities to the community, and encourage states to examine these results specifically for seriously ill populations.
- Signal that caregiver experience and support are priority areas for future HCBS measure development and encourage states to incorporate caregiver-focused questions or modules where feasible.
- Support state use of stratified HCBS quality data to identify and address disparities affecting people with serious illness, including those in rural areas, communities of color, and dual-eligible populations.

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- Provide technical assistance and guidance to help states integrate serious-illness perspectives into HCBS quality measurement and improvement, including linkages to palliative care, hospice, and other community-based serious illness care models.

Thank you for the opportunity to comment on this measure notice. If you have any questions, please contact me, Dr. Marian Grant, Senior Regulatory Advisor, C-TAC, at mgrant@thectac.org.

Sincerely,

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