



*A Program of Families and Communities Rising, Inc.*

May 27, 2026

Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Attention: CMS-2453-NC  
P.O. Box 8016  
Baltimore, MD 21244-1850

**Re:** File Code CMS-2453-NC; RIN 0938-ZB99 — Medicaid Program; 2028 Medicaid Home and Community-Based Services Quality Measure Set

Dear Administrator Oz:

The **ARCH National Respite Network and Resource Center (ARCH)** appreciates the opportunity to comment on the proposed 2028 Medicaid Home and Community-Based Services (HCBS) Quality Measure Set. ARCH strongly supports the Centers for Medicare & Medicaid Services' (CMS) efforts to establish a nationally standardized HCBS quality framework that promotes accountability, comparability across states, and improved outcomes for Medicaid beneficiaries receiving HCBS.

**ARCH also strongly supports and echoes the recommendations submitted by the National Alliance for Caregiving's Caregiver Nation Coalition regarding the absence of family caregiver-focused measures within the proposed HCBS Quality Measure Set.** Family caregivers are foundational to the success and sustainability of HCBS systems nationwide. Yet the proposed measure set does not adequately assess caregiver wellbeing, caregiver inclusion in person-centered planning, or access to essential caregiver supports such as respite care.

As the national organization focused specifically on respite research, policy, and practice, ARCH urges CMS to take additional steps to incorporate respite-related quality measurement into future iterations of the HCBS Quality Measure Set.

### **RESPITE IS A CRITICAL HCBS SERVICE AND QUALITY INDICATOR**

CMS appropriately identifies respite care as a covered HCBS service in the proposed rule. **However, the proposed Quality Measure Set contains no measures that evaluate whether respite services are available, accessible, person and family-centered, responsive to family needs and preferences, effective, or achieving intended caregiver outcomes.**



This omission is significant because **respite is one of the most commonly requested caregiver supports** available within HCBS systems.<sup>1,2</sup> Respite services help sustain family caregiving arrangements, reduce caregiver stress and burden,<sup>3,4,5</sup> improve caregiver wellbeing, strengthen marriages,<sup>6</sup> reduce social isolation,<sup>7</sup> and support individuals with disabilities and older adults to remain safely in their homes and communities.<sup>8,9,10</sup> The absence of respite-focused quality measures leaves states and CMS without the ability to assess whether these services are achieving meaningful outcomes for caregivers, care recipients, families, and HCBS systems overall.

### The Need for Standardized Respite Quality Measures

In 2024, the ARCH Committee for Advancement of Respite Research (CARR) published [Recommended Common Data Elements for Respite Research](#), a national consensus white paper developed to advance standardized measurement of respite outcomes and quality. The white paper specifically calls on state and federal leadership to adopt common respite measures within the HCBS Quality Measure Set and other CMS HCBS quality initiatives.

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<sup>1</sup> National Alliance for Caregiving (NAC) and AARP Public Policy Institute (AARP) (2025). *Caregiving in the US, 2025*. Washington, DC: Authors.

<sup>2</sup> Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services (2026). National Core Indicators — Intellectual and Developmental Disabilities, 2024-25 Data at a Glance: Family Surveys, <https://idd.nationalcoreindicators.org/wp-content/uploads/2026/04/2024-25-Family-Surveys-At-A-Glance.pdf>

<sup>3</sup> Chen, A., Zu, L., and Highfill, C. (2021). Respite services utilization and self-rated health of older family caregivers in the United States: Differences between young-old and old-old caregivers. *Journal of Social Service Research*, 48 (1): 63-72.

<sup>4</sup> Parker, L.J. and Gitlin, L.N. (2021). Does adult day service use improve well-being of Black caregivers of people living with dementia? *Innovations in Aging*, 5 (4): 1-7.

<sup>5</sup> Liu, Y., Almeida, D.M., Rovine, M.J., and Zarit, S. (2018). Modeling cortisol daily rhythms of family caregivers of individuals with dementia: Daily stressors and adult day services use. *J Gerontol B Psychol Sci Soc Sci*, 73 (3): 457-467.

<sup>6</sup> Easler, J.K., Taylor, T.M., Olsen Roper, S., Yorganson, J.B., and Harper, J.M. (2022). Uplifts, respite, stress, and marital quality of parents raising children with Downs Syndrome or Autism. *Intellectual and Developmental Disabilities*, 60 (2) 145-162

<sup>7</sup> McGrane, C., Masson, N. and Martins, D.C. (2021). A group respite pilot project for children with special needs. *Public Health Nursing*, 38(6):1009-1014. doi: 10.1111/phn.12957.

<sup>8</sup> Vandepitte, S., Putman, K., Van Den Noortgate, N., Verhaeghe, S., Annemans, L. (2019). Effectiveness of an in-home respite care program to support informal dementia caregivers: A comparative study. *Int J Geriatr Psychiatry*, 34: 1534-1544.

<sup>9</sup> Gresham M., Heffernan, M., and Brodaty, H. (2018). The Going to Stay at Home program: combining dementia caregiver training and residential respite care. *International Psychogeriatrics*, 1-10.

<sup>10</sup> Avison, C, Brock, D, Campione, J, Hasell, S, Rabinovich, B, Ritter, R, Severynse, J, Yang, D-H (2018). *Final Report prepared for the U.S. Administration for Community Living: Outcome Evaluation of the National Family Caregiver Support Program*. Washington, D.C.: Westat.

The CARR white paper notes that current respite research and evaluation methods do not allow for meaningful comparison of outcomes across studies, respite models, populations, or states. It further emphasizes that consistent use of common data elements is essential to strengthening the evidence base for respite and improving HCBS quality systems.

Importantly, the white paper explicitly recommends that:

*“State and federal programs that fund respite should consider adopting common outcome measures for respite programs to assess the value it brings to individuals and families and also to understand its impact to communities and systems. Additionally, policies that incentivize data collection among respite programs should be explored...” and further encourages “state and national leadership to adopt these measures in the HCBS Quality Measure Set and other HCBS measures developed by the Centers for Medicare and Medicaid Services (CMS).”*

## **RECOMMENDED AREAS FOR RESPITE MEASUREMENT**

ARCH respectfully recommends that CMS begin development and phased adoption of respite-related quality measures using the CARR [Value of Respite Model](#) and accompanying Common Data Elements framework. Potential respite-related measure domains include:

- Caregiver access to respite services
- Timeliness and adequacy of respite availability
- Achievement of caregiver-defined respite goals
- Caregiver satisfaction with respite services
- Inclusion of respite needs within person-centered service planning
- Person and family-centered respite services responsive to individual and family needs and preferences
- Caregiver stress, burden, fatigue, anxiety, and wellbeing outcomes
- Caregiver ability to sustain caregiving responsibilities over time
- Workforce adequacy and provider competence related to respite delivery

The CARR framework also identifies core concepts that align directly with CMS’s broader HCBS quality priorities, including caregiver wellbeing, quality of life, person-centeredness, social connectedness, and access to high-quality services for all HCBS participants.

## **STRENGTHENING PERSON-CENTERED PLANNING THROUGH RESPITE ASSESSMENT**

ARCH particularly supports strengthening LTSS–1 and LTSS–2 to better assess caregiver inclusion and caregiver support needs within person-centered planning processes.

A truly person-centered HCBS system must account not only for the preferences and goals of the HCBS participant, but also for the sustainability of the caregiving arrangement that often makes community living possible. **Assessing whether caregivers have access to respite and whether respite goals are achieved should be considered essential dimensions of HCBS quality.**

## **RECOMMENDATIONS**

ARCH respectfully recommends that CMS:

- Explicitly acknowledge the absence of caregiver and respite-focused measures as a major gap in the final 2028 HCBS Quality Measure Set guidance.
- Utilize the ARCH CARR Common Data Elements framework and Value of Respite Model to inform respite-related HCBS quality measurement development.
- Explore voluntary reporting pathways for respite-related quality measures beginning in the 2028 cycle.
- Include respite researchers, family caregivers, and caregiver advocacy organizations in future HCBS Quality Measure Set Review Workgroups.
- Initiate a targeted public call for caregiver- and respite-focused quality measures in advance of the 2030 HCBS Quality Measure Set cycle.
- Strengthen LTSS–1 and LTSS–2 to assess caregiver inclusion, caregiver support needs, and respite planning within person-centered service plans.

## **CONCLUSION**

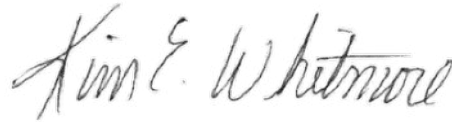
Family caregivers are indispensable partners in Medicaid HCBS systems, **and respite is one of the most important services available to sustain caregiving and community living.** A comprehensive HCBS quality framework should evaluate not only the experiences of HCBS participants, but also the effectiveness of supports that sustain family caregiving arrangements over time.

ARCH appreciates CMS's commitment to advancing HCBS quality and urges the agency to incorporate respite and caregiver-focused measurement into future HCBS Quality Measure Set development. We welcome continued collaboration with CMS and other stakeholders to advance meaningful, standardized respite quality measurement that improves outcomes for caregivers, care recipients, and families nationwide.

Sincerely,



Jill Kagan, MPH  
Director  
ARCH National Respite Network  
and Resource Center  
Email: [jkagan@archrespite.org](mailto:jkagan@archrespite.org)  
Office: 703.256.2084  
[archrespite.org](http://archrespite.org)



Kim E. Whitmore, PhD, RN, CPN  
Assistant Professor, Marquette University  
ARCH Committee for Advancement of  
Respite Research  
Email: [kimberly.whitmore@marquette.edu](mailto:kimberly.whitmore@marquette.edu)  
Phone: 414-403-2699