NATIONAL ALLIANCE FOR CAREGIVING

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May 28, 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 National Alliance for Caregiving appreciates the opportunity to comment on the proposed 2028 Home and Community-Based Services (HCBS) Quality Measure Set. We support the Centers for Medicare & Medicaid Services' (CMS) effort to establish a nationally standardized measure set that promotes comparability of HCBS quality data across States and drives improvement in outcomes for the 8.4 million Medicaid beneficiaries who rely on these services.

Our comments focus on a significant and consequential omission in the proposed 2028 Quality Measure Set: the **near-total absence of family caregivers** from the measure set's framework. Family caregivers are central to the delivery of HCBS in every State and across every population the rule addresses. A measure set that does not capture their experience, their inclusion in person-centered planning, or the supports available to them cannot accurately characterize HCBS quality. We urge CMS to address this gap in the 2028 set to the extent feasible and to establish a clear roadmap for incorporating caregiver-focused measures in the 2030 set.

I. Family Caregivers Are Absent From the Proposed Measure Set

The proposed 2028 Quality Measure Set is built on three categories of measures: (1) two assessment / case management system measures focused on person-centered planning (LTSS–1) and LTSS–2); (2) three administrative-data measures on rebalancing (LTSS–6, LTSS–7, and LTSS–8); and (3) up to 18 participant-reported measures drawn from four experience-of-care surveys (HCBS CAHPS, NCI–AD, NCI–IDD, and POM). None of these measures captures the experience, role, or hardship of family caregivers.

This omission is striking in three respects:

- **Population definitions do not name family caregivers.** The notice describes the populations for which States must report — older adults, people with physical disabilities, people with intellectual and developmental disabilities (IDD), people with serious mental illness, and others (§ 441.312(d)(5)). It does not include family caregivers as a population whose experience CMS will track, even though for several of these groups family members are the primary providers of day-to-day support.
- **The four experience-of-care surveys are participant-reported only.** Each survey proposed for the 2028 set collects the perspective of the beneficiary. None systematically collects information from family caregivers, including in cases where the beneficiary may be unable to self-report (for example, individuals with significant cognitive disabilities), and none asks beneficiaries about their caregivers' inclusion in planning, training, or support.
- **The Workgroup did not surface caregiver measures.** The HCBS Quality Measure Set Review Workgroup that informed this proposal included representatives from State agencies, managed care plans, beneficiary advocates, providers, researchers, and measure developers. The notice does not indicate that family caregivers or caregiver advocacy organizations were represented as a distinct constituency, and none of the 24 measures suggested for addition through the public call for measures focused on caregiver experience or support.

CMS itself acknowledges one parallel gap in footnote 21 (Federal Register p. 22829), noting that "there is a lack of proposed measures in the HCBS Quality Measure Set for children and youth" and that the agency expects to propose measures for that population in the future. **We respectfully submit that the absence of family caregiver-focused measures is a comparably significant gap that warrants the same explicit acknowledgment and forward-looking commitment.**

II. Family Caregivers Are Integral to HCBS Quality and Person-Centered Planning

HCBS exists to allow people to receive services in their homes and communities rather than in institutions. For a substantial share of HCBS beneficiaries — particularly people with IDD, older adults with cognitive impairment, and individuals with complex medical needs — the practical viability of community living depends on the involvement of family members who provide unpaid support, coordinate paid services, and serve as the primary point of continuity across providers, settings, and time.

CMS rightly identifies the proposed mandatory measures LTSS–1 and LTSS–2 as central to assessing the "quality and comprehensiveness of the person-centered planning process," and rightly defends their inclusion as quality (rather than compliance) measures. Yet person-centered planning, as a quality construct, is not complete without consideration of the people the beneficiary chooses to include in that process. Federal HCBS rules already recognize this: a person-centered service plan reflects the individual's strengths, preferences, and goals, and the planning process is expected to include people chosen by the individual, which in practice frequently includes family caregivers. A measure set that assesses only whether a plan was developed and contains specified elements — without any measurement of whether caregivers identified by the beneficiary were meaningfully included — leaves a substantive dimension of plan quality unmeasured.

The notice's discussion of rural HCBS access (Federal Register pp. 22837–22838) further illustrates the issue. CMS cites direct-care workforce shortages and reduced access to paid services in rural areas as reasons to require geographic stratification. In the same areas, family caregivers fill the gaps left by workforce shortages — yet the proposed measure set offers no way to detect whether those gaps are being filled at sustainable cost to families, or whether they are being filled at all. While we appreciate CMS's continued focus on rural and urban stratification, we are concerned by the removal of other demographic stratification categories that could help identify disparities in caregiver experience and support across populations. Preserving broader stratification capabilities will be important as CMS considers future caregiver-focused quality measures.

III. Recommendations

We respectfully offer the following recommendations:

1. **Acknowledge the caregiver gap in the final 2028 measure set guidance.** Consistent with the treatment of children and youth in footnote 21, CMS should expressly identify family and unpaid caregivers as a population for whom additional measure development is needed, and commit to proposing caregiver-focused measures in the 2030 cycle.

2. **Strengthen LTSS–1 and LTSS–2 to capture caregiver inclusion in person-centered planning.** CMS should consider, either through technical specification updates or as a supplemental element, whether the assessment and the person-centered service plan reflect the involvement of family or other unpaid caregivers identified by the beneficiary, and whether the plan addresses the supports those caregivers need to sustain the arrangement. This addition is consistent with CMS's stated rationale for retaining LTSS–1 and LTSS–2 — that effective person-centered planning is integral to ensuring HCBS systems are responsive to beneficiary needs and choices.

3. **Permit voluntary reporting of caregiver-reported measures in 2028.** Several validated instruments collect caregiver experience data, including the AHRQ CAHPS Home Health Care Survey caregiver items, NCI–AD and NCI–IDD family / family-guardian survey instruments, and validated caregiver burden and support measures. CMS's proposal already permits States to report any HCBS CAHPS, NCI–AD, NCI–IDD, or POM measure not included as mandatory; we urge CMS to extend this voluntary-reporting flexibility to caregiver-reported instruments associated with these surveys, and to encourage their use.

4. **Initiate a public call for caregiver-focused measures in advance of the 2030 set.** Section 441.312(c)(3) requires the Secretary to identify newly developed or other measures that should be added to the HCBS Quality Measure Set, including to address gaps. We urge CMS to issue a targeted public call for caregiver-focused measures — spanning caregiver experience of HCBS, caregiver inclusion in planning, caregiver access to training and respite, and caregiver well-being — sufficiently in advance of the 2030 cycle to allow workgroup review and public comment. Maintaining the currently proposed phased implementation timeline for the HCBS Quality Measure Set will also be important to ensuring states and CMS continue building the reporting infrastructure necessary to support future caregiver-focused measurement and quality improvement efforts.

5. **Ensure family caregiver representation on the next Quality Measure Set Review Workgroup.** Future workgroups convened under § 441.312(c)(3) and (g) should include family caregivers and representatives of family-caregiver organizations as a distinct constituency, alongside beneficiary advocates, in order to surface measure concepts and gap areas that the current workgroup composition has not produced.
6. **Consider caregiver presence as a future stratification factor.** CMS notes that it is exploring additional stratification categories beyond the proposed geographic stratification. We recommend that the agency evaluate the feasibility of stratifying selected measures by whether the beneficiary has an identified family caregiver, which would allow States and CMS to detect quality and outcome differences associated with caregiver availability.

IV. Conclusion

HCBS work because of the people — paid and unpaid — who deliver care in homes and communities. A quality measure set that captures only the perspective of the beneficiary, and only the activities of the paid workforce and the case management system, omits a population whose experience is inseparable from HCBS quality itself. We urge CMS to acknowledge this gap in the final 2028 guidance, take the limited steps available within the 2028 cycle to begin closing it, and commit publicly to a measure-development pathway for family caregivers in the 2030 set.

We appreciate CMS's consideration of these comments and welcome the opportunity to provide additional information or assistance as the agency finalizes the 2028 Quality Measure Set.

Sincerely,

The National Alliance for Caregiving

Advocates for Medically Fragile Kids NC

Alzheimer's Association and Alzheimer's Impact Movement

ARCH National Respite Network and Resource Center

The Association for Frontotemporal Degeneration

Careforth

Caring Across Generations

The Coalition to Transform Advanced Care

Diverse Elders Coalition (DEC)

Family Caregiver Center of New Mexico

FamTech.org

Gerontological Society of America

Greater Wisconsin Agency on Aging Resources, Inc.

Hawaii Falls Prevention Alliance

Hawaii Family Caregiver Coalition

Illinois Association of Area Agencies on Aging

Illinois Family Caregiver Coalition

The John A. Hartford Foundation

North Carolina Caregiving Collaborative

North Carolina Serious Illness Coalition

The Self-Direction Center

Utah Commission on Aging

Wisconsin Family & Caregiver Support Alliance