July 31, 2026

The Honorable Mehmet Oz, M.D.
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

RE: Medicaid Program; Community Engagement Requirement for Certain Individuals Interim Final Rule

Dear Administrator Oz,

On behalf of the National Alliance for Caregiving (NAC), thank you for the opportunity to provide comments on the Medicaid Program; Community Engagement Requirement for Certain Individuals Interim Final Rule.

America's 63 million family caregivers are the backbone of our healthcare and long-term care systems. Family caregivers provide hundreds of billions of dollars in unpaid care each year, helping older adults, people with disabilities, and individuals with serious illnesses remain safely in their homes and communities. They serve as care coordinators, medication managers, transportation providers, advocates, and often the primary source of day-to-day support for loved ones with complex health needs.

NAC appreciates the Centers for Medicare and Medicaid Services' (CMS) recognition of the critical role family caregivers play and strongly supports the agency's decision to exclude family caregivers from Medicaid community engagement requirements. We are particularly encouraged by CMS's inclusive approach to defining who qualifies as a caregiver and its recognition that caregiving relationships extend far beyond traditional household and family structures.

At the same time, we are concerned that parts of the rule may unintentionally leave some caregivers and care recipients without the protections Congress intended. We urge CMS to partner with the National Alliance for Caregiving on a standardized caregiver screening approach, revisit its definition of a disabled individual for the caregiver exclusion, and strengthen the framework for identifying medically frail individuals and those with other special medical needs, so that family caregivers and the people they care for can be properly identified and excluded from the requirements.

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Support for the Family Caregiver Exclusion

NAC strongly supports CMS's broad definition of a family caregiver. Caregiving rarely fits neatly into traditional categories. Many caregivers support aging parents, adult children, siblings, neighbors, close friends, or other loved ones who depend on them for assistance. Some live with the individual they support, while others travel significant distances to provide care. Some provide daily hands-on assistance, while others coordinate medical appointments, medications, transportation, and care transitions.

CMS appropriately recognizes these realities by allowing caregivers who are not legally related to the care recipient to qualify for the exclusion and by acknowledging that caregiving can take many forms. We particularly appreciate CMS's decision not to impose minimum hourly requirements on caregivers who reside with or are related to the care recipient. Caregiving is often unpredictable and episodic. A caregiver may spend one week coordinating hospital discharge planning and another managing medications, transportation, and physician appointments. The value of caregiving cannot always be measured by the number of hours provided in a given month.

By recognizing caregiving as a meaningful contribution to families and communities, CMS has taken an important step toward ensuring that caregivers are not forced to choose between maintaining their own health coverage and caring for a loved one.

CMS Should Require a Standardized Assessment Tool to Identify Family Caregivers

NAC urges CMS to use subregulatory guidance and technical assistance to require states to adopt a standardized screening approach for identifying family caregivers, rather than allowing each state to develop its own method under the broad "other information sufficient as determined by the State" standard. Without a standardized approach, states are likely to adopt widely divergent screening processes, producing inconsistent outcomes for individuals in otherwise similar circumstances.

NAC appreciates that CMS already recognized the value of this resource in the Interim Final Rule, noting that the report "Caregiving in the US" (2025) includes examples of screening questions used to identify those caring for a child with disabilities or a serious medical condition, and unpaid caregivers of adults. NAC encourages CMS to build on this recognition by adopting a standardized screening approach drawn from the report.

NAC & AARP's 2025 Caregiving in the US Report includes a question that could serve as the basis for a CMS-required, uniform screening approach:

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> *At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult does not need to live with you.*

Additional Caregiving in the US screening questions could assess the more specific criteria used to define caregivers under the Interim Final Rule (IFR). NAC would welcome the opportunity to partner with CMS on developing a standardized screening mechanism that leverages the Caregiving in the US survey tool.

The CDC's Behavioral Risk Factor Surveillance System (BRFSS) Caregiver Module offers another option. This nine-item instrument, already used by numerous states to identify informal caregivers, captures the relationship, duration, intensity, and type of care provided. It could give states a systematic way to determine both whether an individual qualifies for a caregiver exemption and which exemption category applies.

Any standardized screening approach CMS adopts should be designed to identify every caregiver who could qualify for an exemption. Standardization should ensure consistent, accurate recognition of caregiver status across states — not narrow eligibility or create stricter gatekeeping. CMS should direct states to construct or select assessment tools aimed at capturing the full population of eligible caregivers and should monitor state implementation to ensure tools are not inadvertently screening out individuals who meet the exemption criteria.

Standardized screening is especially important because, as CMS itself acknowledges, family caregiving often occurs in informal settings where documentation may not exist. Unlike other excluded populations, family caregivers are unlikely to have formal records of their caregiving responsibilities, and the IFR offers no reliable, consistent way for them to demonstrate their status. A structured screening tool would close this gap by capturing the relevant facts through a consistent set of questions, rather than requiring documentation caregivers cannot reasonably be expected to have.

NAC also urges CMS to let family caregivers continue establishing their status through self-attestation, consistent with the realities of family caregiving. The IFR permits states to rely on self-attestation for certain purposes through 2027, but caregivers are unlikely to gain access to supporting documentation at any point — before or after that date. CMS should preserve self-declaration as sufficient evidence of caregiver status (absent information indicating otherwise) beyond the period the rule currently allows. A standardized tool and self-attestation work together: the tool provides consistency

across states, while continued reliance on caregiver-reported information ensures eligible caregivers aren't disadvantaged by the informal nature of the care they provide.

CMS Should Close the Gap Between Its Caregiver and Medical Frailty Disability Definitions

NAC is further concerned that the rule defines disability differently depending on whether it is being used to exempt a caregiver or to exempt the individual who needs care. As a result, the very same disability may be recognized as significant enough to exempt the caregiver who supports that individual, while not being recognized as sufficient to exempt the individual themselves. An approach that acknowledges a disability for one purpose but not the other risks leaving the most vulnerable individuals without the protection the exemptions are meant to provide.

NAC therefore urges CMS to more closely align the disability pathway of the medical frailty definition with the "disabled individual" definition used for the caregiver exclusion. Specifically, CMS should issue subregulatory guidance clarifying that an individual who meets the ADA definition of disability at 28 CFR 35.108 qualifies as medically frail under § 435.554(c)(5)(i) on that basis, without being separately required to demonstrate that the disability significantly impairs their ability to comply with the community engagement requirement. At a minimum, CMS should adopt a deeming rule, through subregulatory guidance, providing that where a disabled individual's condition is sufficient to qualify a parent, guardian, caretaker relative, or family caregiver for the exclusion under § 435.554(c)(3), that same individual is deemed to satisfy the medical frailty exclusion under § 435.554(c)(5) for themselves. Either approach would close the gap CMS's current definitions create, ensure consistent treatment of the same disability across the two exclusions, and prevent the untenable outcome of protecting a caregiver while leaving the disabled person they care for subject to a requirement their condition may make impossible to meet.

CMS Should Strengthen the Federal Medical Frailty Standard to Reflect Functional Need

NAC is particularly concerned about CMS's approach to identifying individuals who are medically frail or otherwise have special medical needs. The rule's emphasis on activities of daily living may overlook many individuals whose conditions significantly impair their ability to work despite retaining the ability to perform basic self-care activities. Family caregivers know firsthand that the burden of serious illness often extends far beyond bathing, dressing, and eating. Many individuals require extensive support with transportation, medication management, appointment coordination,

symptom monitoring, cognitive functioning, and other activities that can substantially affect their ability to engage in employment or community activities.

This gap is compounded by the rule's reliance on states to independently determine which diagnoses and conditions qualify as medically frail. Individuals with conditions such as advanced heart failure, cancer, chronic obstructive pulmonary disease, progressive neurological disorders, severe chronic pain, or dementia could face materially different outcomes depending on where they live. Because CMS's own analysis anticipates that a significant share of disenrollments will fall on individuals who are in fact exempt but unable to navigate the documentation process, this state-by-state variation is not a theoretical concern. NAC urges CMS to:

- **Assess medical frailty based on functional impact, not diagnosis alone.** CMS should direct states to treat existing indicators of substantial care needs — including receipt of long-term services and supports, participation in home and community-based services programs, documented functional limitations, and evidence of significant caregiver involvement — as evidence of medical frailty. Where a state's own data show one or more of these indicators, the state should identify the individual as medically frail on an ex parte basis, without requiring additional documentation.
- **Establish a stronger federal foundation for identifying medically frail individuals.** Rather than relying primarily on states to build their own diagnosis lists and qualification frameworks from scratch, CMS should publish a baseline, national set of diagnoses, conditions, and functional indicators that states must treat as presumptively qualifying for the medical frailty exclusion, while allowing states to expand upon that federal floor.

Together, these steps would ensure medical frailty determinations capture the full functional reality of serious illness, promote consistency across states, and reduce the risk that vulnerable individuals lose coverage due to differing state interpretations.

CMS Should Monitor and Publicly Report Caregiver Exclusion Outcomes

NAC encourages CMS to provide additional guidance regarding the monitoring and public reporting of community engagement implementation outcomes. As states begin implementing these requirements, it will be critical to understand whether family caregivers are successfully accessing the exclusions established by Congress and whether eligible individuals are experiencing coverage losses due to administrative barriers rather than ineligibility.

This concern has been echoed by the Medicaid and CHIP Payment and Access Commission (MACPAC), which recently urged CMS to closely monitor implementation of the community engagement requirements to better understand their impact on beneficiaries and state Medicaid programs. Given the significant variation in state verification processes and the absence of a uniform caregiver self-attestation pathway, robust oversight will be particularly important for family caregivers.

NAC recommends that CMS publicly report implementation data that is categorized by exclusion category, including the number and percentage of individuals determined eligible for the family caregiver exclusion. CMS should also report the number of individuals who are identified through automated data sources versus those who must actively seek an exclusion, as well as the number of denials, disenrollments, and procedural terminations involving individuals who subsequently qualify as caregivers upon reconsideration or reapplication.

Without transparent reporting, it will be difficult for CMS and states to identify whether caregivers are being under-identified, inappropriately denied exclusions, or losing coverage because of documentation and verification challenges. Public reporting of these metrics would allow CMS to identify implementation challenges early and ensure that family caregivers are receiving the protections intended under the statute.

Conclusion

NAC appreciates CMS's efforts to recognize the essential role family caregivers play in supporting millions of Americans. We strongly support the caregiver exclusion and believe it reflects an important acknowledgment that caregiving itself is a valuable form of community engagement.

We urge CMS to build upon that strong foundation by ensuring that caregivers supporting individuals with disabilities, serious illnesses, and complex care needs can reliably access the protections Congress intended. Strengthening the definition of a disabled individual and establishing a more consistent approach to identifying medically frail individuals will help prevent inappropriate coverage losses and better reflect the realities faced by caregivers and the people they support every day.

Thank you for your consideration of these comments. We look forward to continued partnership with CMS to ensure implementation of these requirements protect family caregivers and the individuals who depend upon them.

Sincerely,

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