Mehmet Oz, MD, MBA
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

July 30, 2026

Re: CMS-2454-IFC; Medicaid Program; Community Engagement Requirement for Certain Individuals

Dear Administrator Oz,

The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) appreciate the opportunity to comment on the Centers for Medicare & Medicaid Services' (CMS) interim final rule for the Medicaid Program's Community Engagement Requirement for Certain Individuals.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. The Alzheimer's Impact Movement (AIM), a separately incorporated advocacy affiliate, is a nonpartisan, nonprofit organization and works to make Alzheimer's a national priority.

Currently, more than 12.7 million Americans provide unpaid care for people with Alzheimer's or other dementias and in 2025, caregivers of people with Alzheimer's or other dementias provided an estimated 19.6 billion hours of informal — that is, unpaid — assistance, a contribution valued at $446.3 billion.[1] Furthermore, approximately 200,000 Americans under the age of 65 have younger-onset dementia.[2] Both populations are likely to be of a working age and will be directly impacted by the requirements of this interim final rule.

II.E.3.d Definition of a Family Caregiver

The Association and AIM would like to first commend CMS for their community engagement exemption when it comes to family caregivers. The care provided to people with Alzheimer's or other dementia is wide-ranging and, in some instances, all-encompassing and although the care provided by family members of people with Alzheimer's or other dementias can be similar to that provided by caregivers of people with other conditions, dementia caregivers tend to provide more extensive assistance.[3] The unique demands and needs of caregivers of persons living with dementia calls for such an exemption and we appreciate CMS's thoughtful consideration of the extensive burdens many caregivers face.

We are also grateful to CMS for aligning its "family caregiver" definition with the RAISE Family Caregivers Act definition. Additionally, we appreciate CMS's rationale that one overarching definition of terms such as "significant relationship," "regular basis," and "not solely incidental" might not fully

[1] Alzheimer's Association. (2026). *2026 Alzheimer's Disease Facts and Figures*.
[2] Ibid.
[3] Ibid.

address the nuances of caregiving. However, without clear, nationally applicable guidance or model definitions for these terms, states may adopt varying interpretations that create inconsistent access to the exemption. We would therefore urge CMS to provide such guidance or model definitions promoting broad-plain language standards for these terms, giving states a consistent starting point resulting in fewer inconsistencies.

II.E.5 An Individual Who is Medically Frail or Otherwise has Special Medical Needs

The Association and AIM support the exemption for individuals who are medically frail, as many of our constituents with younger-onset dementia would fall within one of the five statutory medically frail categories, including the serious or complex medical condition category, under which CMS notes cognitive impairment may qualify. However, we are concerned that the rule's added requirement of a showing of "significantly impaired," beyond falling within one of the five statutory medically frail categories, could create an inconsistency where a family caregiver qualifies for exemption but the person with the diagnosis does not.

This risk is especially pronounced for individuals with younger-onset dementia, who often fall into a gray area: not severely impaired enough to qualify for exemption from work requirements, yet unable to maintain employment. This gray area often comes into play when individuals with younger-onset dementia apply for disability benefits. Younger-onset dementia can strike individuals in their 40s and 50s, while they are still very much a part of the workforce and often otherwise physically healthy. Despite their age, they still experience impaired memory, reasoning, and judgment. Their ability to learn new information and difficulties with language such as reading, understanding complex conversations, and problem solving also appear early in the course of disease progression. It is easy to misjudge these individuals' level of functioning because they may appear to be young and physically capable. However, as noted above, their ability to learn different skills or remember instructions is compromised. While some of our constituents have navigated the application and review process for disability benefits without a problem, many more have not, often due to the difficulty of reconciling the presence of a progressive neurodegenerative disease in a relatively young, otherwise healthy person. It is imperative in applying the "significantly impaired" standard that it is understood that these individuals are functionally impaired even when it is not visibly evident.

II.H. Assessing Compliance with the Community Engagement Requirement

Finally, the Association and AIM believe additional clarity is needed regarding how family caregivers will be verified in practice. The interim final rule leaves it to each state to determine "what information is considered sufficient to verify" an exception or exclusion when existing data or documentation cannot establish eligibility, which could lead to significant variability across states and make it more difficult for caregivers to verify their status as a specified excluded individual. Beyond the definitional clarity requested above, we would ask CMS to provide states with concrete verification tools to reduce this variability. Specifically, we would urge CMS to create a self-attestation pathway for family caregivers similar to those available for other exemption categories, and standardized caregiver screening questions that states could incorporate into eligibility and renewal processes. Without such tools, states may develop inconsistent verification standards on their own, increasing administrative burden and the risk that eligible caregivers lose coverage due to a lack of documentation rather than an actual lack of qualifying caregiving.

A related concern arises when the caregiver and care recipient are enrolled in different programs, as is common for dementia caregivers supporting a Medicare-enrolled parent. If the state is unable to verify the recipient's information, the burden would then fall to the caregiver to supply the information, which would create an additional burden for caregivers already managing significant caregiving responsibilities.

Thank you for the opportunity to comment. The Alzheimer's Association and AIM would be glad to serve as a resource to CMS as it considers these important issues and how they relate to individuals living with Alzheimer's and related dementias. Please contact Laura Thornhill, Director, Regulatory Affairs, at 202-638-7042 or lthornhill@alz-aim.org if you have questions or if we can be of additional assistance.

Sincerely,

Robert Egge
Chief Public Policy Officer, Alzheimer's Association
President, Alzheimer's Impact Movement