July 23, 2026

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

RE: Medicaid Community Engagement Requirement for Certain Individuals Interim Final Rule with Comment Period (CMS-2454-IFC)

Dear Administrator Oz:

We are writing on behalf of the LEAD Coalition[1] to express our deep concern about the consequences of CMS-2454-IFC (herein referred to as the "interim final rule" or IFR) for millions of individuals living with Alzheimer's disease and related disorders (AD/ADRD), their care partners, and families. The policy changes outlined in the IFR create unnecessary, counter-productive, and potentially dangerous barriers to healthcare coverage and access for some of our nation's most vulnerable individuals.

The LEAD Coalition, in partnership with UsAgainstAlzheimer's, recently released an urgent joint report alerting people living with AD/ADRD, care partners, and their families that recent changes to Medicaid and other federal health programs could jeopardize access to the care and support services on which they rely for their health, well-being, and safety. The report – *Shifting Ground: What Recent Changes to Health Programs Mean for Those Living with Alzheimer's Disease* – explains in clear, accessible terms how recent changes to Medicaid may ripple through the system and affect people living with AD/ADRD, care partners, and families.

[1] Leaders Engaged on Alzheimer's Disease (LEAD Coalition) is a diverse and growing national policy coalition committed to overcoming Alzheimer's disease and related disorders (AD/ADRD), including vascular contributions to dementia, Lewy body dementia, and frontotemporal degeneration. The Coalition serves as the uniting voice of more than 260 member and allied organizations and over 500 researchers to focus the nation's attention on accelerating transformational progress to reduce risk, enhance detection and diagnosis, improve care and support, and develop increasingly effective treatments and eventual cures.

Shifting Ground highlights the real-world implications of federal cuts to Medicaid funding, enacted in 2025 (Public Law 119-21), and explains that the new IFR will create significant, undue administrative barriers for the AD/ADRD community. Regarding the IFR, we emphasize:

- New eligibility requirements threaten continuity of care for individuals living with AD/ADRD
- New administrative burdens significantly elevate risk of care partners losing their own Medicaid coverage
- Elimination of self-attestation in 2028 will increase unwarranted disenrollment for eligible individuals

We provide additional detail about these specific IFR concerns in this letter, though strongly urge CMS to review the *Shifting Ground* report in its entirety before finalizing any changes. It is imperative that CMS leadership and staff hold a firm understanding of the serious and irreversible harms the proposed changes would inflict on individuals living with AD/ADRD, their care partners, and families before any further action is taken – and with that knowledge, we expect CMS to take steps to protect this vulnerable community.

New eligibility requirements threaten continuity of care for individuals living with AD/ADRD

Many individuals living with AD/ADRD depend on Medicaid to access critical healthcare services and supports that allow them to remain safely in their homes and communities. Even temporary disruptions in Medicaid coverage could interrupt or delay access to medications, home- and community-based services (HCBS), and other supports critical to maintaining health, safety, and quality of life. Recent changes to Medicaid eligibility and reporting requirements threaten to undermine this continuity of care, services, and supports.

Beginning in 2027, new community engagement (work) reporting requirements are expected to take effect. While exemptions exist for individuals who are medically frail, the IFR establishes a significantly more burdensome process for demonstrating eligibility for those exemptions. Rather than recognizing the functional limitations associated with progressive cognitive decline for individuals living with AD/ADRD, the rule requires individuals — even those living with an AD/ADRD diagnosis — to affirmatively demonstrate that they are unable to work.

For individuals experiencing cognitive impairment, this new requirement represents an enormous and completely unnecessary administrative hurdle. CMS is requiring people with AD/ADRD to not only be aware of these changes to maintain coverage but also to complete more paperwork to provide proof of their diagnosis ***and*** their inability to meet engagement requirements. A diagnosis of AD/ADRD should itself be sufficient evidence of an exemption, yet CMS is instead compelling individuals with cognitive impairment to navigate complex reporting requirements and compile documentation needed to maintain necessary coverage.

This is a clear example of red tape replacing accessibility – and when this occurs, Medicaid no longer supports the very populations it is intended to serve. CMS must ensure that individuals living with an AD/ADRD diagnosis and eligible for Medicaid do not experience interruptions in care simply due to new administrative requirements.

New administrative burdens significantly elevate risk of care partners losing their own Medicaid coverage

The impact of this IFR extends well beyond individuals living with dementia. Family care partners — who provide the overwhelming majority of care for people living with Alzheimer's disease — also face substantial new administrative burdens under these policies. According to updated data from AARP, approximately 7.3 million family caregivers rely on Medicaid for their own healthcare coverage. These individuals often balance employment, caregiving responsibilities, financial pressures, and their own healthcare needs. Their ability to continue providing care depends in large part on maintaining access to their own health coverage.

Although the IFR proposes an exemption for individuals whose primary responsibility is caring for a family member with a disability (as defined under the Americans with Disabilities Act), those care partners must still comply with ongoing administrative reporting requirements to establish and maintain their own Medicaid eligibility. Meeting these requirements can be extraordinarily difficult for care partners whose daily lives are already consumed by managing medications, coordinating medical appointments, and providing other care and supervision for loved ones living with cognitive impairment or dementia. Through this IFR, CMS is layering yet another obstacle for care partners who are already enduring incredible caregiving demands – and the consequences will be extremely detrimental to the health and well-being of the care partner and their loved ones living with AD/ADRD. Time, energy, and money spent on government paperwork is at the expense of caregiving.

Elimination of self-attestation in 2028 will increase undue disenrollment for eligible individuals

The IFR's proposed approach to eliminating self-attestation further amplifies these concerns. Self-attestation by Medicaid beneficiaries and care partners can provide a practical and efficient means of verifying exemptions while reducing unnecessary paperwork. Instead, the IFR gives states the option to permit self-attestation only during 2027. Beginning in 2028, CMS will no longer allow states to rely on self-attestation for these purposes. Eliminating this flexibility is likely to increase documentation requirements, delay eligibility determinations, and contribute to avoidable coverage losses. Navigating these additional procedural requirements will be incredibly burdensome for individuals living with cognitive impairment and their care partners and will be a major driver of inappropriate Medicaid disenrollment for eligible individuals.

Conclusion

Families living with AD/ADRD already face extraordinary emotional, physical, and financial challenges. Medicaid is a lifeline allowing millions of these individuals to receive necessary healthcare and supportive services. Coverage loss will delay diagnosis, treatment, and care; reduce access to long-term services and supports; increase care partner strain; and ultimately contribute to preventable emergency department visits, hospitalizations, and nursing home placements. These outcomes are not only harmful for individuals and families but also increase healthcare spending by shifting costs toward more intensive and expensive care settings.

As implementation of Medicaid changes begin, **we respectfully urge CMS to take steps to protect individuals living with AD/ADRD, their care partners, and families from avoidable coverage disruptions.** We encourage CMS to adopt practical pathways for demonstrating medical frailty, minimize unnecessary documentation requirements, and maintain flexible verification options, including self-attestation.

Medicaid should support families facing AD/ADRD instead of creating new obstacles. Policies designed to strengthen program integrity must account for the realities faced by individuals with AD/ADRD, their care partners, and families.

Thank you for your attention and continued commitment to protecting access to care for the AD/ADRD community. We welcome the opportunity to work with you to ensure that Medicaid policies promote both accountability and fair access to care for our nation's most vulnerable populations.

For any questions or additional information, please contact Ian Kremer, executive director of LEAD Coalition, ikremer@leadcoalition.org, or Courtney Wallin, federal policy director of the LEAD Coalition, cwallin@leadcoalition.org.

Sincerely,

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