

CAREGIVER NATION COALITION

February 24, 2026

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

RE: Data Strategy for Family Caregiver Verification Under H.R. 1 Community Engagement Requirements

Dear Dr. Oz:

The Caregiver Nation Coalition respectfully submits this letter to inform the Centers for Medicare & Medicaid Services (CMS) as it develops guidance for implementing the family caregiver exemption under H.R. 1, the budget and tax bill passed by Congress and signed into law by the President. We offer actionable recommendations for data sources and verification strategies that will help ensure eligible family caregivers maintain access to Medicaid coverage and essential home and community-based services.

The Critical Role of Family Caregivers in America

Family caregivers serve as the backbone of our nation's long-term services and supports infrastructure. An estimated 63 million Americans provide care to family members, friends, and neighbors with chronic or other health conditions, disabilities, or age-related needs. These individuals perform a wide spectrum of tasks—from helping with personal care like bathing and dressing to managing medications, coordinating medical appointments, and navigating complex health systems. Research consistently shows that while many caregivers find meaning in their role, they also experience considerable strain: financial hardship affects nearly half, and emotional stress impacts roughly two-thirds of this population.

Approximately 7.3 million working-age adults (18 to 64) are family caregivers who depend on Medicaid for their own healthcare coverage—roughly 15 percent of all caregivers in this age group. These individuals typically dedicate substantial time to caregiving, frequently exceeding 20 hours weekly, and most shoulder these responsibilities without help from other family members or professional aides. The intensity of care they provide is significant: on average, they assist with multiple activities of daily living, a level of support that many states recognize as equivalent to nursing home-level care needs.

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Why Medicaid Coverage Matters for Caregivers

Health coverage through Medicaid allows caregivers to address their own medical needs while fulfilling their caregiving responsibilities. With continuous coverage, caregivers can obtain preventive care, manage ongoing health conditions, and access mental health services that help them cope with the demands of their role. This coverage is not merely beneficial for individual caregivers—it supports the broader care ecosystem.

When caregivers lose health coverage, the consequences extend beyond their personal health. Family caregivers help stabilize the long-term care system by supplementing a strained direct care workforce; caregivers losing coverage undermines that stabilizing role and shifts costs onto already overburdened public programs. A caregiver whose own health is neglected and deteriorating may be unable to continue providing care, potentially accelerating the need for costly institutional placements for their care recipient(s). This dynamic creates a ripple effect across Medicare, Medicaid, and state budgets. Protecting caregiver coverage is therefore both a family health issue and a matter of sound fiscal policy.

The Data Challenge for Ex Parte Verification

A central implementation challenge for the H.R. 1 family caregiver exemption is identifying reliable data sources that would allow states to verify caregiver status automatically, without requiring beneficiaries to submit additional documentation. The law directs states to use available data to make these determinations wherever possible, and robust verification processes will be critical to preventing eligible caregivers from losing coverage due to procedural barriers.

This letter identifies concrete data sources and verification approaches that CMS can include in their guidance as recommendations to states for their consideration, reducing administrative complexity for both state agencies and Medicaid beneficiaries. Because the RAISE Family Caregivers Act definition of family caregiver noted in H.R. 1 is new to state Medicaid law, most states do not currently have systems designed to identify family caregivers under this definition in a standardized or automated manner. Without clear federal guidance on permissible data sources and verification pathways, states may default to manual documentation requirements that increase administrative burden, delay exemptions, and place eligible caregivers at heightened risk of inappropriate coverage loss.

Recommended Verification Data Sources

We have identified multiple data sources that states can leverage to verify family caregiver status, including through automated processes. These sources fall into three categories based on their accessibility and the level of coordination required.

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A. State Medicaid and Waiver Program Data

The following data sources exist within state health and human services systems and can be most readily incorporated into eligibility determination processes:

Data Source	Description & Value for Verification
Structured Family Caregiving (SFC) Programs	Represents the most reliable verification source. Individuals enrolled in Medicaid-funded caregiver programs have undergone formal identification and assessment. Provider payment records provide definitive documentation of active caregiving.
Paid Family Caregiver Programs	HCBS and other waivers, state plan option, state plan, and state-only funded programs that compensate family members for providing care generate claims data, service plans, and payment records that document caregiver relationships and ongoing service provision.
Caretaker Relative Eligibility Data	Beneficiaries who qualified for Medicaid through the caretaker relative pathway have already been determined to be providing care. This existing eligibility data can support verification of the new exemption category.
LTSS Assessment Data	Functional assessments and care planning documents often identify family caregivers (“natural supports”) supporting the assessed individual. When a Medicaid applicant appears as a designated caregiver in these records, this information can support exemption verification.
HCBS Applications and Care Plans	These documents frequently capture information about unpaid family support being provided alongside paid services, creating another avenue for identifying caregivers within existing state data systems.
Managed Care Plan Records	Medicaid managed long-term care plans often collect caregiver information as part of care coordination activities. States can work with contracted plans to access this data for verification purposes.

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B. Federal Partner Data Sources

Additional data sources maintained by federal agencies or federally-funded programs can be accessed through interagency data sharing agreements. We encourage CMS to facilitate collaboration between states and the Administration for Community Living (ACL), Department of Veterans Affairs (VA), and Social Security Administration (SSA) specifically for the purposes of caregiver verification:

Data Source	Description & Value for Verification
National Family Caregiver Support Program (NFCSP)	Area Agencies on Aging track participants in this Older Americans Act program, which provides respite, counseling, and training and other support to caregivers. Program enrollment records document caregiver status.
VA Caregiver Programs	The VA operates multiple caregiver support programs, including the Program of Comprehensive Assistance for Family Caregivers, and the Veteran Directed Care (VDC) Program. Enrollment data identifies individuals serving as caregivers to veterans with service-connected disabilities and participation in different VA caregiver support programs can confirm caregiver status.
SNAP Exemption Data	Some states track caregiving-related exemptions from SNAP work requirements. Where this data exists, it can support cross-program verification of caregiver status.
Medicare Caregiver Training Claims	Medicare now covers caregiver training services. States may be able to use this claim data to confirm caregiver status.

C. Additional State-Level Data Sources

Depending on state-specific programs and policies, additional data sources may be available:

Data Source	Description & Value for Verification
Electronic Health Records	Over 40 states have enacted CARE Act legislation or taken administrative action requiring hospitals to document a patient's designated caregiver. Health systems may be able to share this information with

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	state Medicaid agencies through appropriate data use agreements to support exemption verification.
State Caregiver Tax Credit Records	Several states provide tax credits for family caregivers. Tax filing records identifying credit claimants can help confirm caregiver status.
Medicare Advantage Plan Records	Medicare Advantage plans often collect caregiver information as part of care coordination activities or delivery of Supplemental Caregiver Support services. States can work with contracted plans to access this data for verification purposes.
Lifespan Respite Care Programs	Some states require identification of caregivers to participate in respite programs. Participation confirms that an individual is providing ongoing care to someone with support needs.

Potential Documentation & Screening Approaches

When automated verification is not feasible, states will need streamlined processes for beneficiaries to document their caregiver status. We recommend CMS provide guidance encouraging the following approaches as options:

Documentation Approach	Strategic Guidance for CMS
Self-Attestation	States should accept a beneficiary's own statement of caregiver status as sufficient for initial exemption determination, consistent with existing Medicaid practices for other eligibility factors. Simple mechanisms like checkboxes on enrollment forms can facilitate this process while minimizing procedural barriers.
Task-Based Guidance	Provide beneficiaries with clear descriptions of qualifying caregiving activities, including assisting with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and medical/nursing tasks, so they can accurately assess whether they meet the exemption criteria.
Third-Party Statements	Allow submission of brief statements from healthcare providers, social workers, or care managers

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	confirming that the beneficiary provides regular assistance to a person with care needs.
Accessible Reporting Channels	Ensure that beneficiaries can report or verify their caregiver status through multiple channels—online portals, mobile applications, telephone hotlines, mail, and in-person at local offices. Multiple channels should be designed to reduce access barriers. CMS could encourage states to set expectations around plain-language materials, accessibility, and reasonable wait/processing times.

Key Policy Recommendations for the Interim Final Rule

As CMS develops the interim final rule required by June 2026, we respectfully urge the agency to address the following:

Maintain the Statutory Definition: The rule should not adopt a narrower interpretation of “family caregiver” than what H.R. 1 provides through its reference to the RAISE Family Caregivers Act. The statutory language intentionally encompasses caregivers of individuals of any age with chronic conditions or other health conditions, disabilities, or functional limitations.

Maximize Exemption Duration: Drawing on precedents from flexibilities that exists for other programs like SNAP, guidance should encourage states to grant exemptions for the longest permissible periods, reducing the frequency of reverification and providing stability for caregivers.

Focus on Caregiving Responsibilities: Exemption eligibility should be determined based on whether an individual provides care, not on a minimum number of hours. Neither the RAISE Family Caregivers Act definition nor H.R. 1 impose an hours threshold.

Promote Federal Data Sharing: CMS should coordinate with HHS component agencies and other federal departments to establish data sharing pathways that enable states to access caregiver identification data from VA, SSA, ACL, and other relevant sources for the specific purpose of verification.

Address Privacy and Artificial Intelligence (AI) Safeguards: Guidance should acknowledge the need for states to execute appropriate data use agreements and ensure Health Insurance Portability and Accountability Act (HIPAA) compliance when accessing health-related information for verification purposes. Where AI-enabled tools are used to support verification, CMS should encourage states to apply strong security controls, limit data to the minimum necessary, and maintain human oversight.

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Minimize Verification Lookback Periods: States should be encouraged to require only one month of compliance demonstration for both initial applications and renewals, rather than multiple months, to reduce barriers for caregivers accessing or maintaining coverage.

Conclusion

The community engagement requirements in H.R.1 represent a fundamental shift in Medicaid policy, but the law clearly intends to protect family caregivers from losing coverage. Implementation approaches that fail to effectively identify and exempt eligible caregivers would undermine both the statute's purpose and the stability provided by our nation's caregivers.

The Caregiver Nation Coalition is prepared to assist CMS with additional information, data, and expertise as the agency develops implementation guidance. We welcome the opportunity to work together to ensure that the millions of family caregivers who depend on Medicaid can continue to access the coverage they need while continuing to care for their loved ones.

Thank you for your consideration of these recommendations.

Respectfully submitted,

Caregiver Nation Coalition Members

National Alliance for Caregiving
AARP
ALive, But Not Well
Alliance for Aging Research
ALS Association
Alzheimer's Association and
Alzheimer's Impact Movement
Association for Frontotemporal
Degeneration
Association of California Caregiver
Resource Centers
Benjamin Rose
Bubba's Light, Inc.
California Coalition on Family
Caregiving
Careforth

Diverse Elders Coalition (DEC)
Elizabeth Dole Foundation
Family Caregiver Center of New Mexico
Georgia Council on Aging
Gerontological Society of America
Greater Wisconsin Agency on Aging
Resources, Inc.
Hawaii Family Caregiver Coalition
Jewish Federations of North America
Justice in Aging
Keeping It REAL Caregiving
National Academy of Elder Law
Attorneys (NAELA)
National Health Council
National Respite Coalition
NC Caregiving Collaborative

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North Carolina Serious Illness Coalition
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The John A. Hartford Foundation
The Self-Direction Center
USAging
Utah Commission on Aging
Wisconsin Aging Advocacy Network
Wisconsin Family & Caregiver Support Alliance