

CAREGIVER NATION COALITION

November 4, 2025

The Honorable Dr. Mehmet Oz, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Dr. Oz,

On behalf of the Caregiver Nation Coalition (CNC), powered by the National Alliance for Caregiving (NAC), we urge the Centers for Medicare and Medicaid Services (CMS) to protect family caregivers as policymakers develop guidance for states to implement the community engagement provisions (also colloquially referred to as work requirements) for adults ages 19 to 64, which were included in the FY 2025 budget reconciliation law, OBBBA (Pub. L. 119-21).

The Caregiver Nation Coalition, which brings together more than 120 stakeholder organizations representing caregiving, aging, disability, and patient advocacy stakeholders across the caregiving continuum, is eager to work with CMS to advance a shared commitment to honor and elevate the vital role of **America's 63 million family caregivers** who help older adults, people with disabilities, and people with serious illness manage their health and wellness.¹ **According to the recently released report from NAC and AARP, *Caregiving in the US 2025*, that number reflects a dramatic 45 percent increase in the last decade.** As you know, family caregivers are the **backbone of our healthcare and long-term care systems and economy, providing an estimated \$600 billion in uncompensated care each year** while serving as essential partners to both patients and healthcare providers.²

The FY 2025 budget reconciliation law, OBBBA (Pub. L. 119-21) makes significant changes to federal and state Medicaid funding policies, including implementing the community engagement provisions largely affecting adults who are part of the Medicaid expansion and some 1115 waiver populations. As of July 2025, 41 states and the District of Columbia have expanded Medicaid under the ACA, covering nearly 20 million individuals.

¹ AARP and National Alliance for Caregiving. *Caregiving in the US 2025*. Washington, DC: AARP. July 24, 2025.
<https://www.caregivingintheus.org>

² Reinhard, Susan C., Selena Caldera, Ari Houser, and Rita B. Choula. *Valuing the Invaluable 2023 Update: Strengthening Supports for Family Caregivers*. Washington, DC: AARP Public Policy Institute. March 8, 2023.
<https://doi.org/10.26419/ppi.00082.006>

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We believe that federal and state **regulators have a critical opportunity to protect a population of up to 8 million family caregivers** who rely on Medicaid, by creating clear **guidance to states that the RAISE Family Caregivers Act's**

broad definition of family caregivers creates significant flexibility to exempt family caregivers from community engagement requirements.

The OBBBA includes and relies on the RAISE Family Caregivers Act's broad definition of family caregivers, creating flexibility for states to exempt eligible family caregivers from Medicaid community engagement requirements. Federal and state regulators should seize this opportunity to issue clear guidance protecting up to 8 million family caregivers who rely on Medicaid.

As CMS creates implementation guidance to states, we urge regulators to incorporate policy provisions to protect family caregivers including:

- Leverage the broad statutory language in the OBBBA to exempt eligible family caregivers
- Automatically exempt family caregivers in Medicaid consumer-directed, self-directed, or Veterans-directed care programs
- Simplify verification processes using self-attestation and existing data sources to prevent coverage losses due to administrative burden
- Encourage stakeholder input through public comment on federal guidance (due by June 2026) and state implementation plans

Federal Guidance Critical in Giving States Flexibility for Family Caregivers

The specific consequences of mandatory community engagement requirements for Medicaid enrollees will likely vary by state and will depend on state-specific interpretation of federal implementation guidance. As the agency works on developing guidance, we urge CMS to incorporate flexibility in how states determine exempted populations, including family caregivers.

Community Engagement Requirement Exemptions and Family Caregivers in the OBBBA:

Section 71119, Medicaid Community Engagement Requirements, of the OBBBA states that a “*Specified excluded individual...means an individual, as determined by the State (in accordance with standards specified by the Secretary)—who—... is the parent, guardian, caretaker relative, or family caregiver (as defined in section 2 of the RAISE Family Caregivers Act) of a dependent child 13 years of age and under or a disabled individual.*”³ The RAISE Family Caregivers Act defines a family caregiver as “*an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health*

³ One Big Beautiful Bill Act, Pub. L. 119-21, § 71119 (2025).

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condition, disability, or functional limitation.”⁴ The bipartisan, bicameral RAISE Family Caregivers Act, was signed by President Donald Trump in 2018. Because the RAISE Family Caregivers Act broadly defines family caregivers, there is significant room for interpretation as the agency and state policy makers consider OBBBA implementation details.

Family Caregivers Should Be Exempt From Community Engagement Requirements

Sixty-three million Americans serve as family caregivers who help children, youth, young adults, older adults, people with disabilities, and people with serious illness manage their health and wellness,⁵ which reflects a dramatic 45 percent increase in the last decade. Up to 8 million family caregivers rely on Medicaid services for healthcare, including more than one million who are older adults between ages 50 and 64.⁶ Requiring millions of family caregivers to adhere to the community engagement provisions outlined in the OBBBA risks the health of both caregivers, who may no longer have access to healthcare, and their care recipients if their primary caregivers are required to seek/find employment instead of providing ongoing essential care.

Considerations for Exempting Family Caregivers

As CMS drafts guidance and states consider implementing statutory requirements in OBBBA, policy makers have important opportunities to mitigate burdensome impacts for caregivers and their families. These opportunities include, but may not be limited to:

1. Leveraging the broad statutory language regarding family caregivers and their care recipients of all ages as defined in the RAISE Family Caregivers Act to exempt family caregivers from community engagement/work requirements.
2. Automatically exempt caregivers participating in Medicaid consumer-directed or self-directed care programs or Veterans-directed care programs from community engagement/work requirements.
3. Require state administrative and reporting activities for Medicaid recipients to be sufficiently simple and rely on available information to facilitate easy verification and protect Medicaid eligibility/enrollment for family caregivers.
4. Ensure that advocates and subject matter experts have an opportunity to review and comment on federal and state implementation guidance.

⁴ RAISE Family Caregivers Act, Pub. L. 115-119, § 2 (2018).

⁵ AARP and National Alliance for Caregiving. Caregiving in the US 2025. Washington, DC: AARP. July 24, 2025.

<https://www.caregivingintheus.org>

⁶ https://justiceinaging.org/wp-content/uploads/2023/04/Medicaid-Work-Requirements_Red-Tape-That-Would-Cut-Health-Coverage-for-Older-Adults.pdf

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Fortunately, the OBBBA is broadly inclusive of all types of caregivers and their care recipients by referencing the RAISE Family Caregivers Act definition, which leaves sufficient room for both federal and state policy makers to exempt eligible caregivers from work requirements and avoid unintended consequences of limiting access to essential home and community-based services.

Furthermore, all 50 states and DC have Medicaid consumer-directed or self-directed home and community-based care (HCBS) programs, and nearly all states, DC, and Puerto Rico have Veterans-Directed Care (VDC) programs.^{7, 8} Federal and state regulators can mandate that family caregivers who are participating in—or qualify for—the Medicaid or VA consumer-directed programs are automatically exempt from Medicaid work requirements.

Policy makers also have the opportunity to ensure that administrative and verification processes for Medicaid enrollees are not onerous for caregivers. States that have previously implemented employment or education requirements for Medicaid recipients have repeatedly demonstrated that Medicaid coverage losses are as much a product of the “paperwork”—rather than the actual work—requirements. The OBBBA requires states to verify that affected individuals meet work requirements or exemption criteria at application and at renewal, but the law is not directive regarding that process.

The statute also requires that states establish verification processes that rely on existing data available to the state without requiring applicants to submit additional administrative information.⁹ Federal and state regulators have the flexibility to implement less burdensome reporting procedures to streamline eligibility and exemption determinations. This flexibility will be especially important to exempt eligible family caregivers, as caregivers do not often have paperwork or other formal declarations of their caregiving status. Clearly established policies deploying strategies such as self-attestation, maximizing the use of available data sources, and simplifying documentation submission can ensure that family caregivers relying on Medicaid to maintain their own health do not fall through the cracks of a changing Medicaid program.¹⁰

As CMS develops implementation guidance, subject matter experts and advocates can provide essential analysis about statutory implications at a local, state, and federal level. Public review and comment on draft guidelines will be essential to ensuring efficient implementation and mitigating unintended consequences for affected populations, including family caregivers and their care recipients.

⁷ <https://www.kff.org/medicaid/how-do-medicaid-home-care-programs-support-family-caregivers>

⁸ <https://acl.gov/programs/veteran-directed-home-and-community-based-services/veteran-directed-home-community-based>

⁹ *ibid.* 3.

¹⁰ <https://www.cbpp.org/research/health/how-to-streamline-verification-of-eligibility-for-medicaid-and-snap>

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The inclusion of the RAISE Family Caregivers Act definition of family caregiver in the OBBBA offers a critical opportunity to prevent unintended Medicaid coverage losses among eligible Americans providing essential family care. Federal guidance will be decisive in determining whether states protect or inadvertently harm the millions of family caregivers who serve as the backbone of America's healthcare system.

Again, we urge CMS to ensure that implementation guidance honors the immense commitment of millions of family caregivers, respects the incredibly difficult work that caregiving is, and protects family caregivers from Medicaid coverage losses. We are eager to collaborate with you and your agency leadership to ensure family caregivers are valued and supported. Please contact Elaine Dalpiaz, Vice President, Government Affairs and Policy at elaine@caregiving.org, with questions and to schedule a conversation.

Sincerely,

National Alliance for Caregiving
AARP
Access Living
Aging Services Consultant
Agnes McCarthy Caregiver Foundation
Allies for Independence
ALS Association
AlterDementia LLC
Alzheimer's Los Angeles
American Association of Caregiving Youth
American Association on Health and Disability
American Federation of State, County & Municipal Employees
American Geriatrics Society
American Society on Aging
Association for Frontotemporal Degeneration
Association of California Caregiver Resource Centers
Association of Cancer Care Centers (ACCC)
Autism Society of America
Benjamin Rose
BWTE
California Coalition on Family Caregiving
Care in Action
Caregiving Daughters.net
Center for Caregiver Serenity
Center for Medicare Advocacy
CommunicationFIRST
Compassion & Choices
Diverse Elders Coalition

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Easterseals, Inc.
Elizabeth Dole Foundation
Family Caregiver Center of New Mexico
Gerontological Society of America
Gimme A Break
Grantmakers In Aging
Greater Wisconsin Agency on Aging Resources
Hand in Hand: The Domestic Employers Network
Hawaii Family Caregiver Coalition
Lakeshore Foundation
Marin Center for Independent Living
Milwaukee County Commission on Aging
MyFriendBen
National Academy of Elder Law Attorneys (NAELA)
National Association of Social Workers (NASW)
National Committee to Preserve Social Security and Medicare
National Council on Aging
National Domestic Workers Alliance
National Down Syndrome Congress
National Health Council
National Indian Council on Aging (NICOA)
National Respite Coalition
Network of Jewish Human Service Agencies
New Disabled South
NHCOA
North Carolina Caregiving Collaborative
Peer Voices United-Sacramento
Riccio Pick Me Ups
RRF Foundation for Aging
SAGE
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The Arc of the United States
The John A. Hartford Foundation
The Negative Space
United Spinal Association of Pittsburgh
USAging
Village to Village Network
Well Spouse Association
Western New York Integrated Care Collaborative
Wisconsin Aging Advocacy Network
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