

ADVOCACY TOOLKIT: Ensure Family Caregivers are Exempt from Medicaid Work Requirements

On December 8, 2025, CMS [issued guidance](#) to states regarding implementation of work requirements (often referred to as “community engagement”) for Medicaid programs across the U.S. Work requirements will unduly burden family caregivers and have a devastating impact on those who rely on family caregivers to live in their homes.

Work requirements are a result of H.R. 1, the budget reconciliation bill, Pub. L. 119-21, that was signed into law in July 2025. This law outlined a small group of those who can be exempted from work requirements – including family caregivers. As defined by the RAISE Family Caregivers Act, a family caregiver is “*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 condition, disability, or functional limitation.*”

ADVOCACY OPPORTUNITY - NOW IS THE TIME TO ACT!

As states begin to operationalize work requirements and report requirements, we encourage family caregiving advocates to contact their Governor, State Medicaid Director, and State Aging Departments.

The Caregiver Nation Coalition created a template letter that outlines several strategies that state policymakers can take to broadly exempt family caregivers from burdensome Medicaid work requirements.

We encourage state advocates to personalize this letter by:

- Adding state-specific messaging, including information about family caregiver populations in your state.
- Including state-specific caregiver information from the recently released [Caring Across States](#) report and pull in [state-specific statistics](#) to support your messages.
- Sharing caregiver stories that show the importance of exempting family caregivers from Medicaid work requirements.

Thank you! State policymakers need to hear from you on this issue. If your organization focuses more heavily on the disability or Veterans communities, we encourage you to dive deeper into those topics and customize your letters to state officials to better the needs of your organization and your constituencies.

IDENTIFYING YOUR STATE POLICYMAKERS

[State Governors](#)

[Medicaid Directors](#)

MESSAGING RESOURCES

- Caregiver Nation Coalition sign-on letter [urging CMS to exempt family caregivers from work requirements](#) in implementation guidance, (November 4, 2025)
- National Alliance for Caregiving policy brief, “[The Invisible Workforce: How Medicaid Work Requirements Overlook the Labor of Family Caregiving](#)” (May 2025)
- National Alliance for Caregiving policy brief, “[The Role of Medicaid in Supporting Family Caregivers](#)” (February 2025)
- [Justice in Aging Medicaid Defense Resources](#) and [Mitigating the Harms of Medicaid Work Requirements for Older Adults: Tools for State Advocates](#)
- [AARP Letter](#) to CMS urging exemption of family caregivers from Medicaid community engagement requirements (November 7, 2025)
- [Other NAC and Caregiver Nation Coalition resources on Medicaid](#)

DATA RESOURCES

- [Caregiving in the US 2025: Caring Across States](#)
- [Caregiving in the US State Profiles](#)
- [Family Caregivers and Own Health Insurance Coverage, by State, 2025](#)

TEMPLATE LETTER

ADD ORGANIZATIONAL LETTERHEAD

DATE

The Honorable GOVERNOR NAME
ADDRESS
CITY, STATE, ZIP

CC: STATE MEDICAID DIRECTOR
STATE AGING DIRECTOR

Dear Governor LAST NAME:

On behalf of the ORGANIZATION, we urge you to protect family caregivers as our state implements Medicaid work requirements (also referred to as community engagement requirements) and verification processes as required by the FY 2025 federal budget reconciliation law, H.R. 1 (Pub. L. 119-21).¹

Our nation's 63 million² family caregivers are the backbone of our healthcare and long-term care systems. Family caregivers also provide an estimated \$600 billion in uncompensated care each year while serving as essential partners to both patients and healthcare providers.³

According to the new report, [Caring Across States](#), released in October 2025 by the National Alliance for Caregiving and AARP, there are an estimated XX (*find the number of caregivers in your state in the [Caring Across States fact sheets](#) and add citation*) family caregivers in STATE.

INSET INFORMATION ABOUT YOUR ORGANIZATION AND HOW YOU SUPPORT FAMILY CAREGIVERS - INCLUDE STATE-SPECIFIC STATISTICS. We are eager to work with you and our state health leaders to advance a shared commitment to elevating the vital role of family caregivers in their work to support families across our state.

ADD A CAREGIVER STORY HIGHLIGHTING THEIR VITAL ROLE AND/OR INCLUDE INFORMATION ABOUT HOW [CAREGIVERS SERVE THEIR LOVED ONES](#) IN YOUR STATE (*e.g., In Arizona, nearly half of all caregivers—roughly 600,000*

¹ H.R. 1, Pub. L. No. 119-21 (2025).

² AARP and National Alliance for Caregiving. Caregiving in the US 2025. Washington, DC: AARP. July 24, 2025. <https://www.caregivingintheus.org>

³ 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>

Arizonians—are high-intensity caregivers assisting with complex activities of daily living including bathing, dressing, medication assistance, etc. For example, Jane Doe of small town, AZ, spends 35 hours a week as the primary caregiver helping her aunt with dementia remain safely at home where they both want to be. Jane cannot work because of the time that she must care for her loved one, and she relies on Medicaid expansion for her own health benefits. Were Jane to be subject to work requirements, she would have to choose between caring for her family and her own well-being.)

Nationally, up to 8 million family caregivers rely on Medicaid services for healthcare, including more than one million older adults between ages 50 and 64.⁴ Requiring millions of family caregivers to adhere to the community engagement provisions outlined in H.R. 1 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.

(If your state has expanded Medicaid, insert: As of July 2025, 41 states, including STATE, have expanded Medicaid. According to a [May 2025 report from the Commonwealth Fund](#), these requirements are expected to result in XXX losing coverage in STATE (see table 2).

(If your state has NOT expanded Medicaid insert: Even though STATE has not expanded Medicaid, a [May 2025 report from the Commonwealth Fund](#), estimates a \$X economic loss because of the policy resulting in increased economic hardship for families and family caregivers in STATE (see table 2).

Community Engagement/Work Requirement Exemptions

On December 8, 2025, the Center for Medicare and Medicaid Services [issued guidance](#) to states regarding implementation of work requirements (also referred to as community engagement requirements) for Medicaid programs across the U.S. Work requirements will unduly burden family caregivers and have a devastating impact on those who rely on family caregivers to live in their homes.

Work requirements were included in H.R. 15, the budget reconciliation bill, Pub. L. 119-21, that was signed into law in July 2025. This law outlined a small group of those who can be exempted from work requirements – including family caregivers. As defined by the RAISE Family Caregivers Act, a family caregiver is “*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 condition, disability, or functional limitation.*”⁶

⁴ Ibid.

⁵ Section 71119, Medicaid Community Engagement Requirements, of the One Big Beautiful Bill Act, Pub. L. 119-21, 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.*”

⁶ RAISE Family Caregivers Act, Pub. L. 115-119, § 2 (2018).

STATE policymakers should rely on the RAISE Family Caregivers Act's broad definition of family caregivers to exempt caregivers from work requirements. State leaders should automatically exempt family caregivers who provide care to their care recipients through various Medicaid and Veterans Administration (VA) programs:

- Medicaid home and community-based care (HCBS) -- all expansion states allow HCBS
- Medicaid consumer-directed programs
- VA consumer-directed programs
- Other Medicaid state plan and waiver services through which caregivers are identified and provide care (e.g. Medicaid structured family caregiving programs)

Verification Processes

We also urge you 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.

H.R. 1 requires that states establish verification processes that rely on existing data available to the state without requiring applicants to submit additional administrative information.⁷ STATE officials should implement strategies such as screening forms that ask about caregiving, self-declaration, maximizing the use of available data sources, and simplifying documentation submission to ensure that STATE’s family caregivers relying on Medicaid to maintain their own health do not fall through the cracks of a changing Medicaid program.⁸

Again, we urge you to honor the immense commitment of STATE’S family caregivers, respect the incredibly difficult work that caregiving is, and protect family caregivers from Medicaid coverage losses. We are eager to collaborate with you and your team. Please reach out to POINT OF CONTACT NAME AND EMAIL with questions or if you would like to discuss this vital issue further.

Sincerely,

SIGNATURE
NAME, TITLE
ORGANIZATION

⁷ *ibid.* 2.

⁸ <https://www.cbpp.org/research/health/how-to-streamline-verification-of-eligibility-for-medicaid-and-snap>

Community Engagement Requirements – Advocacy Checklist

- Review the [Caregiver Nation Network Advocacy Toolkit](#).
- Draft and send a letter to your State Medicaid Director, Governor, State Aging Director, Offices on Aging and Disability, and relevant state lawmakers overseeing Medicaid, using the [toolkit template](#). Personalize the letter with state-specific caregiving data and stories where possible.
- Share a copy of the letter with [your U.S. Senators and Representatives \(find out who your legislators are at this link\)](#) to elevate state-level concerns.
- Collect stories from family caregivers who rely on Medicaid ACA expansion coverage. Stories may be included in your letter, referenced in an op-ed, or shared on social media.
- Identify 1–2 family caregivers willing to speak with state officials or the media about the impact of potential Medicaid coverage loss on themselves and their families.
- Use data from [Caregiving in the U.S. 2025: Caring Across the States](#) and [your state's caregiving data profile](#) to educate policymakers.
- Amplify your advocacy by sharing letters, caregiver stories, and data through social media.

Policy Implementation Recommendations to States

State Options

Don't implement work requirements prior to January 1, 2027

Urge your state to minimize the compliance and reporting periods:

- 1 month look back period for new applicants
- 1 month of compliance for current enrollees
- Routine eligibility checks/renewals no more frequently than every 6 months

Verification Options

- Accept self-declarations to verify eligibility for exemptions
 - Most family caregivers are not in any database
 - Most family caregivers won't have documentation
- Don't use payroll data or work history to deny exemption
 - Family caregivers who are paid by Medicaid or who are also employed should still be eligible for the exemption
- Test before enforcing work requirements
 - Can Medicaid enrollees, including family caregivers, understand notices, application questions, and reporting procedures?
 - Are data and verification systems working properly?

Describing the Caregiver Exemption

DO	Don't
<ul style="list-style-type: none"> • Use the RAISE Family Caregivers Act Definition • Specify that caregivers of older adults are included in the definition • Provide examples of assistance with daily activities 	<ul style="list-style-type: none"> • use language that limits or narrows the exemption: <ul style="list-style-type: none"> • "dependent" or "relative" • "full time" or "prevents work" • Focus only on children or parent/child caregiving • Focus only on "hands on" care • Require care recipient to be disabled or have specific diagnosis

NOTE: To watch the February 26, 2026, webinar titled "The New Landscape: H.R. 1 and What's at Stake for Family Caregivers" click [this link](#).