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The New Landscape: H.R. 1 and What's at Stake for Family Caregivers

Introduction: Elaine Dalpiaz, VP Government Affairs & Policy, NAC

February 26, 2026

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Today's Agenda

- Overview of new Medicaid work requirements
- Identify the pain points for family caregivers
- Advocacy actions in several states
- Data sources for the family caregiver “data gap”
- Q&A
- Time for state advocates to share updates, strategies & tactics

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Medicaid Work Requirements Overview of H.R.1

- Congress passed it and the President signed H.R.1 in July 2025.
- Mandates every state implement work requirements for most adults ages 19 to 64 enrolled in Medicaid expansion or similar coverage.
- Adults must meet 80 hours of qualifying activities a month.
- States must implement work requirements by January 1, 2027; however, states may implement sooner.
- 41 states (including DC) have expanded Medicaid.
- CMS issued guidance in December 2025.

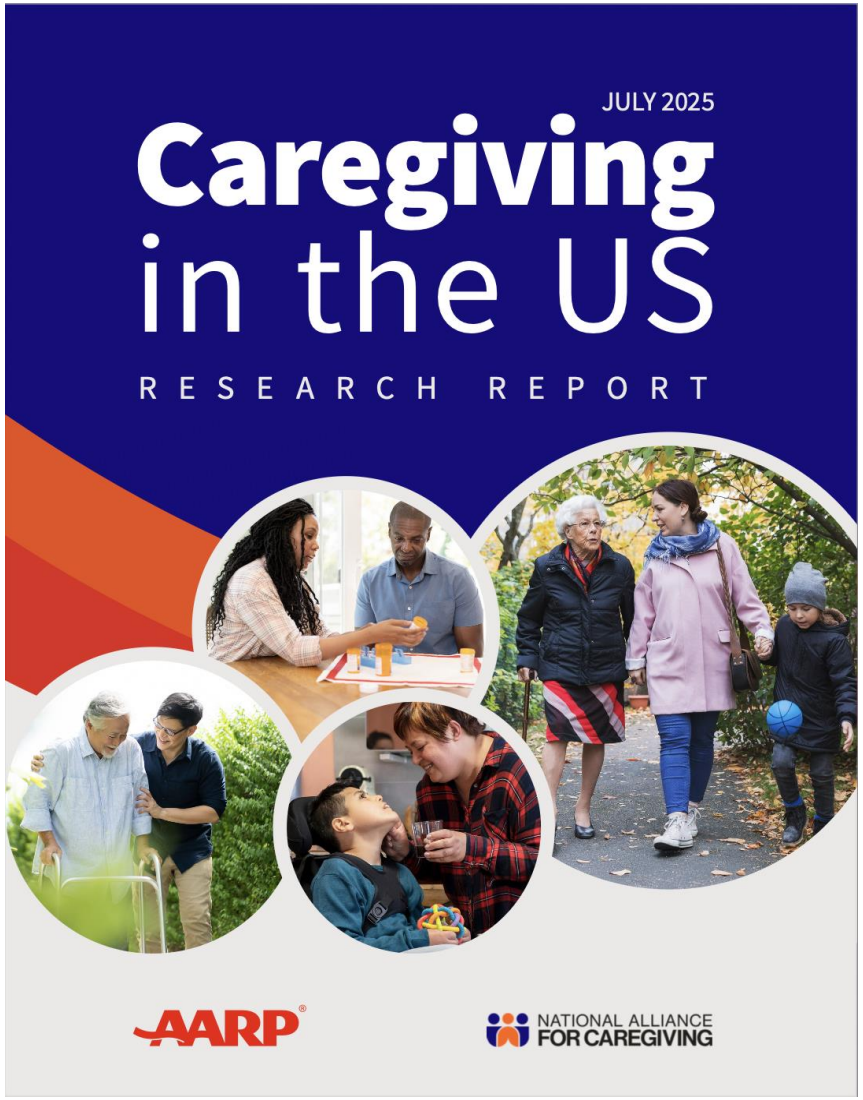
Family Caregiver Exemption and Definition from H.R. 1

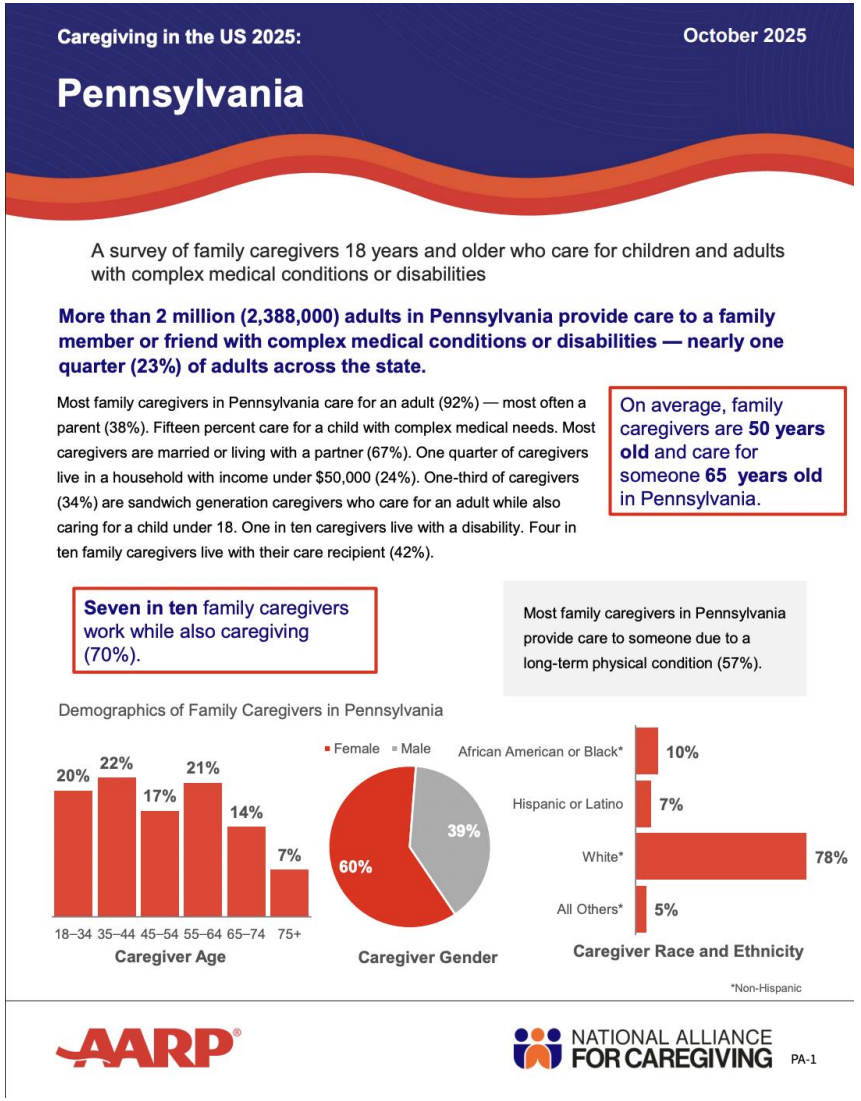
"A Medicaid enrollee “who is the parent, guardian, caretaker relative, or family caregiver (as defined in section 2 of the RAISE Family Caregivers Act) of a dependent child 13 years of age and under or a disabled individual” is statutorily exempt from work requirements.

The RAISE Family Caregivers Act definition: “… 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.”

CGUS Data Tells A Powerful Story

National and State Data





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Speakers for Today's Webinar

Jennifer Dexter, Vice President for Policy at the National Health Council

Natalie Kean, Director of Federal Health Advocacy at Justice in Aging

Brendan Flinn, Director of Long-term Services and Supports, Public Policy Institute, AARP

Moderating the Q&A and Discussion Session:

Toni Gingerelli, Director of Policy and Advocacy, NAC

The New Landscape: HR1 and What's at Stake for Family Caregivers

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2025 H.R. 1 Community Engagement Timetable

Activity	Date
Initial Guidance Released	December 12, 2025
Interim Final Guidance	June 2026
States Required to Begin Implementation	January 1, 2027 (Can Begin Earlier)

NHC Recommendations to CMS and States for H.R. 1 Implementation

- State systems must minimize the potential for errors in adjudicating Medicaid eligibility.
- Guidance and rulemaking should allow the full extent of state flexibilities included in H.R. 1.
- Where possible, the agency should encourage states to allow self-attestation in new applications and renewals.
- Guidance and rulemaking should clearly and fully define who is exempt from community engagement requirements, minimizing administrative burden on states and individuals.
- Exemption processes must be manageable and reasonable.
- Technical guidance must specify how to work with employers, schools and training centers, treatment programs, and nonprofit volunteer sponsors to partner with states and Medicaid recipients to provide compliance with community engagement requirements.
- Ensure states provide the assistance that Medicaid beneficiaries will need to meet program requirements.
- CMS should closely monitor implementation of state applications and renewals and respond to states that show inappropriate coverage losses.

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Thank you!

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FIGHTING SENIOR POVERTY THROUGH LAW

Advocacy Strategies for State Implementation of Work Requirements

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February 26, 2026

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Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources.

Since 1972 we've focused our efforts primarily on fighting for people who have been marginalized and excluded from justice, such as women, people of color, LGBTQ+ individuals, and people with limited English proficiency.

Not All Medicaid Enrollees Are Subject to Work Requirements

- Only "applicable individuals" as defined in the statute must comply
  - Medicaid expansion population (41 states) or
  - Individuals in expansion-like programs (e.g. Georgia Pathways, Wisconsin)
- H.R. 1 includes 3 types of exceptions from completing work activities:
  - Categorical Exclusion: Not enrolled in Medicaid expansion or similar pathway
  - Individual Exemptions: Exempted from “applicable individual” definition for all or part of a month
  - Short-term hardship exception: At state option

Exemptions for Caregivers

- Parent/guardian/caretaker relative/family caregiver of
  - dependent child age 13 or under OR
  - a disabled individual
- Caregivers of a disabled individual include caring for older adults
- Defines family caregiver using the RAISE Family Caregiver Act definition:
  - "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"
  - Broader than those caring for “dependent” or “disabled individual”

Advocacy Strategy: Contact Your State Officials

Who	How	What
• Medicaid agency • Medicaid Advisory Committee (MAC) & Beneficiary Advisory Council (BAC) • Offices on Aging or Disability • Governor • State legislators	• Letter (NAC template) • Public meetings or forums	• Stories and examples • Recommendations • Ask to review draft materials

Recommendations: State Options

- Don’t Implement work requirements prior to Jan. 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

Recommendations: Describing the Caregiver Exemption

DO	Don't

• 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
	• use language that limits or narrows the exemption:
	  • "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

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Recommendations: Verification

- 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 understand notices, application questions, and reporting procedures?
  - Are data and verification systems working properly?

Use Stories and Examples

- Illustrate who exemptions should cover
  - Who is caregiving but not might identify themselves as a caregiver?
  - What does caregiving look like?
  - Who are caregivers supporting that are not in their household or are not related?
- Example:
  - "I do self work with Instacart because …I get to pick and choose the days I'm able to work and dealing with my dad, getting in that nursing home and also dealing with my mom now because she's getting into that phase where she's needing more doctor appointments." -- 52-year-old man
    - Source: KFF's The Debate Over Federal Medicaid Cuts: Perspectives of Medicaid Enrollees Who Voted for President Trump and Vice President Harris

Advocacy Strategy: State Legislation

- Work with partners and state lawmakers to put limits and protections into state law
- Nebraska Appleseed worked with partners to introduce bills aimed at mitigating coverage loss
  - LB723, LB777, LB812
- Advocate against legislation aimed at making work requirements and other Medicaid eligibility rules more onerous

Justice in Aging Resources

- Mitigating the Harms of Medicaid Work Requirements for Older Adults: Tools for State Advocates
- What's in the Budget Reconciliation Act of 2025 and What Does it Mean for Low-Income Older Adults' Access to Health and Long-Term Care?

Using Data to Protect Family Caregivers Under OBBBA's Medicaid Community Engagement Requirements

Brendan Flinn, Director of Long-Term Services and Supports, AARP

February 2026

“Ex Parte” Verification in OBBBA Medicaid Work Requirements

- OBBBA requires states to use of reliable information “without requiring, where possible,” the person to submit more paperwork to be considered compliant or exempt from the requirements.
- This is referred to as *ex parte*, or administrative, verification.
- Such verification can help demonstrate an enrollee’s compliance with work requirement rules without them needing to act.
- States have flexibility related to which data sources they use.
- Greater use of ex parte verification methods reduces the number of family caregivers who will need to receive the exemption themselves.
- Key method to prevent inappropriate, procedural disenrollments.

Family Caregivers and Ex Parte Verification

- OBBBA does not list specific datasets that states must or must not use for ex parte verifications.
- The statute calls for states to “use reliable information” that are “in accordance with standards established by the Secretary”.
- Guidance from HHS is forthcoming and looms as an X factor- but states are still empowered to act.
  - Policy decisions (e.g., which data sources to include)
  - Operational decisions (e.g., pursuing data use agreements)

Ex Parte Verification Potential Data Sources for Family Caregivers

Within state/local government

- Medicaid HCBS applications and care plans
- Medicaid HCBS programs that pay family caregivers
- States Units on Aging and Area Agencies on Aging records (incl. NFCSP participants)
- SNAP caregiver data
- Guardianship records

Ex Parte Verification Potential Data Sources for Family Caregivers

From other sources

- MLTSS and/or MA records
- Hospital/health system EHR data (such as those from state CARE Act policies)
- Data from other providers
- VA caregiver program data
- SSA representative payee data

Ex Parte Verification and Data Privacy

- Family caregiver data potentially used in ex parte compliance efforts generally involve personal health information and/or personally identifiable information.
  - In some cases, HIPAA compliance will be necessary.
- States must ensure data privacy and security when developing ex parte policies.
- Both states and data steward partners need to make sure that data stays secure, in the right hands, and used only for the identified purpose.
- This will require careful planning, agreement development, and execution.
- Data access processes are a good reason for states not to impose the community engagement requirements before January 2027.

Guardrails for Use of Tech/AI

- States may employ AI and other technologies to support OBBBA implementation, including work requirement compliance efforts.
- If using AI/automation, states should:
  - Ensure reliability and bias evaluation
  - Require a human in the loop
  - Never terminate coverage based solely on algorithmic output.
- **No Medicaid enrollee, including those who are family caregivers, should be disenrolled based solely on AI determinations.**

AARP Activity and Resources

- AARP Public Policy Institute report: How States Can Support Family Caregivers Under Medicaid's Community Engagement Requirements, https://www.aarp.org/pri/topics/health/coverage-access/medicaid-community-engagement-requirements-family-caregiver-coverage/
- AARP Public Policy Institute state fact sheets: Medicaid and Its Role for Older Adults: 51 State Fact Sheets, https://www.aarp.org/pri/topics/health/coverage-access/state-fact-sheets-medicaid-older-adults/
- AARP Public Policy Institute data visualization: Older Adults Ages 50-64 Who Rely on Medicaid Expansion https://www.aarp.org/pri/topics/health/coverage-access/older-adults-rely-medicaid-expansion/
- AARP letter to CMS on OBBBA Medicaid work requirements: https://www.aarp.org/content/dam/aarp/politics/advocacy/2025/11/aarp-cms-family-caregiver-exemption-medicaid-community-engagement-requirements-nov-2025.pdf
- AARP news article on OBBBA Medicaid work requirements: Why Medicaid Work Requirements Could Hurt Older Adults the Most, https://www.aarp.org/advocacy/medicaid-work-requirements-hurt-older-adults/

AARP | aarp.org/caregiving

Caregiving Resources

- AARP Care for the Caregiver Guide **aarp.org/careforthecaregiver**
- AARP Family Caregiving Site – **aarp.org/caregiving**
- AARP Family Caregivers Discussion Group on Facebook at **facebook.com/groups/aarpfamilycaregivers**
- Online Community Resource Finder – **aarp.org/crf**
- AARP Local – **aarp.org/localcaregiving**

Caregiver Health and Well-Being

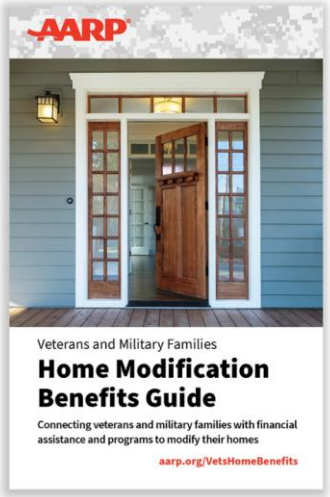
Guidance and support for caregivers to help achieve a better life balance, enhanced self-care and improved mental health

Becoming a Caregiver

Establishing a support system and researching common issues can help anyone starting out

Join Local Caregiving Events

Discover AARP caregiver events and free guides to help you stay supported and informed



Military and Veteran Caregiver Resources

- AARP Veterans Resources - **aarp.org/vetresources**
- VA Caregiver Support Program: **www.caregiver.va.gov**
- AARP VMF Caregiver Guide: **aarp.org/caringforvets**
- AARP VMF Caregiver Financial Workbook: **aarp.org/vmfcaregivermoney**
- AARP Family Caregiving Site – **aarp.org/caregiving**

AARP®

Thank you!

- Contact information:

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Questions & Answers

Please drop any questions in the Q&A chat.

State Sharing and Collaboration

Thank You!

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