



# CAREGIVING RULEMAKING AND OTHER ADMINISTRATIVE ACTIONS AT A GLANCE

The following overview spotlights selected recent regulations proposed or finalized by the U.S. Department of Health and Human Services (HHS) and other administrative actions, most of which AARP has engaged on to increase support for family caregivers. These rules and other policies take or propose to take important steps to assist family caregivers and ease the challenges of caregiving. While these steps represent important progress, more is needed to support our nation's caregivers.

Collectively, they represent important progress, but additional action is also needed. In the months and years ahead, AARP will continue to advocate for federal regulations and policy that provide needed support for family caregivers.

Following this list of recent rules proposed or finalized and other administrative actions is an overview of additional federal policy changes that AARP would like to see to support caregivers.

## ISSUE

## BACKGROUND ON ADMINISTRATION ACTION

### National Strategy to Support Family Caregivers

The federal government's 2022 National Strategy to Support Family Caregivers, released in September 2022, includes a robust set of actions to support caregivers, many of which AARP has long advocated. For example, it calls for the inclusion of caregivers in their loved ones' hospital discharge processes and for greater access to respite care services. The strategy will be updated every two years, in part based on public input from organizations like AARP and others and advisory work at the federal, state and local levels. Below are a couple examples of actions taken under the National Strategy.

HHS has published four reports on caregivers and long-term services and supports:

- [Future Changes in Caregiving Networks: How Family Caregivers and Direct Care Workers Support Older Adults with Needs for Long-Term Services and Supports at Present and in the Future.](#)
- [The Economic Value of Unpaid Care Provided to Older Adults Who Need Long-Term Services and Supports.](#)
- [Diversity in Caregiving Needs and Networks: Differences by Race-Ethnicity in the Care Older Adults Receive.](#)
- [Change in Caregiving Networks Over the Course of Disability](#)

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#### National Strategy to Support Family Caregivers (con't)

The Administration for Community Living (ACL) awarded funding to **five entities** to help support implementation of the National Strategy across its five goals. Together the five entities form the National Caregiver Support Collaborative that will provide technical assistance and capacity building focused on the National Family Caregiver Support Program and Native American Caregiver Support Program.

#### President's Executive Order

The April 2023 Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers includes:

1. Discharge planning
2. Hospital at home
3. Access to Medicare information for the family caregivers (1-800-Medicare)
4. Demonstration testing supports for family caregivers
5. Strengthening the Department of Veterans Affairs Program of Comprehensive Assistance for Family Caregivers to expand access.

This is AARP's statement on the Executive Order.

#### Discharge Planning Memo

In June 2023, the Centers for Medicare & Medicaid Services (CMS) released a memo in relation to hospital discharge to home (with home health care) or other post-acute care settings. The memo follows up on the hospital discharge planning provision in the April 18 Executive Order. Specifically, the memo reaffirms and outlines the responsibilities hospitals have to engage caregivers at discharge. AARP's long-held belief is that when a person you care for goes home from the hospital and has home health care or leaves the hospital and goes to a nursing home for rehab, the hospital should include family caregivers as an active partner in the process (with appropriate consent of the individual and their caregiver).

#### Hospital at Home Programs

CMS included a question in a waiver submission for the Acute Hospital Care at Home waiver for each hospital to provide a process for how the hospital will engage family caregivers and support people during a patient's hospital care in the home. AARP has advocated for the inclusion of family caregiver considerations in Hospital at Home programs, including by submitting a statement for the record to a Congressional hearing held on the topic of enhancing care at home.

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#### Medicare Paying Providers to Train Family Caregivers

For the first time, CMS is paying for caregiver training services (CTS) – time spent solely for training family caregivers. This policy - that went into effect on January 1, 2024 - is a monumental step in acknowledging the essential role family caregivers play. Making caregiver training services available through Medicare is important to ensure access to these critical services for caregivers who need them. AARP submitted [comments](#) and led a [coalition letter](#) of 60 groups in support of the caregiver training proposal. CMS also included caregivers and family members the principal illness navigation (PIN) services provisions, which focuses on helping patients with a serious, high-risk illness navigate their health care and decisions.

#### Medicare Paying for Caregiver Supports in Medicare Shared Savings Program

The Medicare Shared Savings Program will pay an Accountable Care Organization advanced investment payments to help improve the quality and efficiency of items and services furnished to beneficiaries and provide an opportunity for entities in rural and underserved areas to come together to form an Accountable Care Organization. Patient caregiver supports are explicitly included as a potential use of funds, including:

- Caregiver counseling or support groups
- Caregiver training and education
- Respite care

#### CMS Innovation Center Guiding an Improved Dementia Experience (GUIDE) Model

The CMS Innovation Center will conduct a nationwide voluntary model that tests interventions to support beneficiaries with dementia and their caregivers. Providers with patients who need dementia care could take part in the test program and would be assigned a care navigator to help connect them to key supports in the community, ranging from health care to meals and transportation. They would also have access to a 24-hour support line and other services. Caregivers would have access to education and training programs and respite services to help them take time off from their caregiving responsibilities. Applications to participate were due to CMS at the end of January 2024.

#### 2024 CMS Medicare Hospital Outpatient Rule

CMS solicited feedback in the 2024 proposal on whether it would be appropriate to include caregiver-focused services in the list of recognized services for partial hospitalization and intensive inpatient services. AARP submitted [comments](#) in support of including caregiver-focused services in Partial Hospitalization Program (PHP) and Intensive Outpatient Program (IOP) and include costs for such services in the calculation of PHP and IOP per diem payment rates. The provision was included in the final rule.

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#### Medicaid Access Rule

The Medicaid access proposed rule would create a new Beneficiary Advisory Group (BAG) whose membership includes individuals with direct experience supporting Medicaid beneficiaries, such as family members and paid or unpaid caregivers. As currently proposed, one quarter of BAG members would serve on the state's Medicaid Advisory Committee. The proposed rule would also allow a beneficiary to provide written consent to a family caregiver to file a grievance on their behalf. AARP submitted [comments](#) in July 2023 including other ways to support family caregivers.

#### Medicaid Managed Care Rule

The Medicaid managed care proposed rule is meant to increase accountability and transparency in managed care programs, amplify the voices of beneficiaries and caregivers, and ensure that program information is easy to understand and available in multiple languages.

AARP submitted [comments](#) that included the need for meaningful, usable information on a state's managed care website, and the need to incorporate direct program feedback from Medicaid enrollees and their family caregivers.

#### Supporting Family Caregivers with Medicaid Home and Community-Based Services (HCBS) American Rescue Plan Act (ARPA) Funds

The Administration announced (as part of a broader announcement) that 29 states are investing in efforts to offer family caregivers training, respite, new training websites, counseling support groups, and other services from the Medicaid HCBS investments in the American Rescue Plan Act. States are planning to spend \$1.3 billion on activities focusing on supporting caregivers. CMS also released guidance to states on direct support worker registries, which was included in the April 18 Executive Order. See the [CMS press release](#), [CMS slides](#), and [CMS guidance](#).

#### **CMS Briefs Supporting Family Caregivers Caring for Adults with Intellectual & Developmental Disabilities**

Supporting Adults with I/DD and Their Aging Caregivers, released in June 2023, aimed to assist state Medicaid and partner agencies in their efforts to address the needs of adults with intellectual and developmental disabilities (I/DD) and their aging caregivers. The collection includes the following briefs:

- [How State Agencies Can Anticipate and Meet the Needs of Adults with I/DD and Their Aging Caregivers](#)
- [State Policies and Practices to Support Person-Centered Planning Across the Lifespan for Individuals with I/DD and Their Aging Caregivers](#)
- [State Policies and Practices to Support Aging Caregivers of Adults with I/DD](#)
- [State Spotlights: Supporting Adults with I/DD and Their Aging Caregivers](#)

## AARP's vision for more federal progress to support family caregivers

### STRENGTHEN SUPPORT FOR FAMILY CAREGIVERS:

- Make providing care easier, including through expansion and increasing awareness of resource navigation tools, reducing red tape for family caregivers as in the Alleviating Barriers for Caregivers Act (ABC Act), and examination of policy changes to improve the navigability of resources. The Connecting Caregivers to Medicare Act would help inform people about Medicare's voluntary option for Medicare beneficiaries to allow family caregivers to access their health information through 1-800-MEDICARE. This can make it easier for caregivers to communicate with Medicare to help their loved one or advocate on their behalf.

**AARP worked with the bill's sponsors on the bipartisan, bicameral introduction of the Connecting Caregivers to Medicare Act in the U.S. House of Representatives and U.S. Senate in January 2024.**

- Ensure family caregivers are included in their loved one's care and provide them with the caregiver training, education, and support they need, including in Hospital at Home programs, Medicare more broadly, and in measures of provider engagement with and support of family caregivers.
- Increase and ensure access to services and supports for all family caregivers. Use culturally appropriate family caregiver needs assessments to help target and tailor needed supports to family caregivers efficiently and effectively. Increase access to respite care and address disparities and other barriers to accessing support.
- Increase funding for the National Family Caregiver Support Program and Native American Caregiver Support Services, No Wrong Door/Aging and Disability Resource Centers, and the Lifespan Respite Care Program.

### IMPROVE THE MEDICARE HOME HEALTH BENEFIT:

- Waive the homebound requirement for Medicare home health coverage to expand access to the benefit.
- Survey Medicare beneficiaries using home health care and their family caregivers about their access to and experience with the benefit.
- Develop quality measures that capture information about family caregiver status, caregiver involvement in a beneficiary's care, support provided to the caregiver, and family caregiver experience of care.
- Address any identified disparities in access to and quality of care.
- Ensure appropriate oversight and enforcement of the current Medicare home health benefit so eligible Medicare beneficiaries receive necessary care, including home health aide visits.

### Caregiver Tax Credit:

Create a new federal tax credit of up to \$5,000 annually for eligible working family caregivers to help address the financial challenges of caregiving. The Credit for Caring Act could help eligible family caregivers caring for loved ones of all ages offset the cost of some caregiving expenses such as a home care aide, adult day care, home modifications, assistive technology, respite care, transportation, or other supports that help

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their loved ones. Unlike the existing child and dependent care credit, this new credit would help family caregivers who do not live with the person they are assisting or who care for non-dependents.

**AARP worked with the bill's sponsors on the bipartisan, bicameral introduction of the Credit for Caring Act in the U.S. House of Representatives and U.S. Senate in January 2024.**

An additional way to help provide financial relief for caregivers is the Lowering Costs for Caregivers Act that would allow a family caregiver with a health savings account, flexible spending account, health reimbursement account, or Archer Medical Savings Account to use the funds in such account for qualified medical expenses for a parent or parent-in-law.

### **Establish a Respite Benefit in Medicare:**

Establish a Medicare respite benefit that could provide important assistance to beneficiaries and their family caregivers. Another intermediate step could be adding an in-home respite benefit as part of the Medicare hospice benefit, which currently only includes a limited inpatient facility respite benefit.

### **Strengthen Supports For Family Caregivers In Medicaid:**

Include an assessment of the needs of family caregivers who voluntarily provide assistance to those receiving Medicaid HCBS and provision of caregiver support based on such assessment. Support could include respite, training, education, counseling, the option in self-direction programs for family caregivers to be paid to provide care, as well as family caregiver experience of care measures, and more.

### **Strengthen The Long-Term Care Workforce:**

Incentivize states to grow their HCBS workforce through improved recruitment and retention. This could include grants or enhanced federal matching rates to implement HCBS workforce initiatives including increased pay and benefits, paid leave, core and advanced training for direct care workers, supervisor training, and job improvement initiatives.

### **Paid Leave:**

Millions of Americans do not have access to paid family leave – forcing workers to decide between remaining employed or caring for their loved one. As America struggles with a shortage of workers, ensuring this type of flexibility is vital to ensuring a strong workforce while meeting the needs of older loved ones. Federal leave programs must include family leave, not just parental leave.

### **Identify Family Caregivers:**

Identify family caregivers of Medicare beneficiaries or who may be Medicare beneficiaries themselves, such as through including their names and contact information in health and long-term care records, screening to identify family caregivers as part of the Welcome to Medicare preventive visit and Medicare annual wellness visits, and adding caregiver status to the list of standardized patient assessment data elements required for reporting by skilled nursing facilities and other Medicare post-acute care providers. Caregiver identification may also provide an opportunity to identify and provide needed support the caregiver, such as education and training, especially around care transitions.

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Learn more: [aarp.org/caregiving](https://aarp.org/caregiving)