

2024 Report to Congress

Progress Report: Federal Implementation of the 2022 National Strategy to Support Family Caregivers



From the:
**Recognize, Assist, Include, Support, and Engage
Family Caregiving Advisory Council**
and the
Advisory Council to Support Grandparents Raising Grandchildren



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Letter From Alison Barkoff

Each year, more than 53 million Americans provide a broad range of assistance to support the health, quality of life, and independence of an older adult or person with a disability. In addition, millions of grandparents — and an unknown number of other kinship caregivers — open their arms and homes each year to children who cannot remain with their parents. The number of family caregivers continues to increase as the populations of disabled people and older adults grow, and the overdose crisis and other issues create thousands of new “grandfamilies” each year.

Family caregivers are the backbone of the nation’s system of long-term care — replacing the support they provide with paid services would [cost an estimated \\$600 billion](#) each year. But when they do not have training, support, and opportunities for rest and self-care, their health, well-being, and quality of life often suffer. Their financial future can also be put at risk; lost income due to family caregiving is estimated to be a staggering \$522 billion each year. And if they are unable to continue to provide care, the people they support may have no option but to move to nursing homes and other facilities or, for children, to enter foster care. This deprives the person receiving support of their right to live in their community and often results in poorer health, usually at an increased cost to public programs.

We must improve the way we support family caregivers in this country.

The National Strategy to Support Family Caregivers was released in 2022 as a first step in a coordinated national effort to address this critical public health issue. The strategy was developed by the advisory councils established by the [RAISE Family Caregiving Act](#) and the [Supporting Grandparents Raising Grandchildren Act](#) with extensive input from stakeholders, including family caregivers and the people they support. It presented a vision, established goals, and provided recommendations for ensuring family caregivers have the support and resources they need. The strategy also included commitments from 15 federal agencies to nearly 350 actions to implement these recommendations. Recognizing that federal agencies alone cannot address the issue, the strategy also includes more than two dozen recommendations for legislative and policy changes, like federal legislation to improve paid family leave policies and expand access to services, along with over 150 recommendations that can be implemented by states, communities, businesses, philanthropy, and others.

ACL is pleased to provide this report, which focuses on federal implementation of the strategy. Today, nearly all of the 350 federal actions have been completed or are in progress, and federal agencies have committed to almost 40 new actions since the strategy’s release nearly two years ago. This has created new programs and initiatives to directly support caregivers, improved efficiency and coordination, opened doors to international engagement and collaboration, and more.



In addition, the 2022 National Strategy has catalyzed partnerships and collaborations that are accelerating our progress toward achieving its vision. All branches and levels of government, advocates and stakeholder groups representing a wide variety of interests and industries, and family caregivers and the people they support have come together to support the implementation and ongoing development of the strategy — exactly as intended.

These accomplishments reflect the Biden-Harris Administration’s unwavering commitment to strengthening the care infrastructure, which has been demonstrated through a wide range of policy initiatives and new investments in expanding access to home and community-based services, growing and strengthening the direct care workforce, supporting family caregivers, making affordable, quality child care more available to working families and more. The strategy and the actions across federal government to implement it are important contributions to the administration’s broader efforts, which work together to strengthen the U.S. economy, reduce health care costs, and improve lives.

The responsibility for improving caregiver support touches every sector of our society — from federal, state, and local government to business and philanthropy, to advocacy organizations, to each of us. After all, as former First Lady Rosalynn Carter so often reminded us, caregiving is a universal issue — nearly all of us will either need or be a family caregiver at some point in our lives, and many of us will experience both.

We now have an incredible opportunity to advance this critical work. First, we have unparalleled support from our nation’s leaders. The bipartisan support for the RAISE Act and for improving the lives of caregivers gives us a real path for improvement. President Biden called out the needs of America’s caregivers in his State of the Union address the last two years, emphasizing the importance of solidifying the care infrastructure to support and strengthen our nation’s families. His [Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers](#) reinforced this further.

We also have extraordinary momentum. The COVID-19 pandemic brought the need to support family caregivers to the forefront of conversations at [dining room tables and board rooms](#) across the country. Coalitions, such as the [Act on RAISE](#) and [Care Can’t Wait](#) campaigns, have formed to accelerate implementation of the strategy and advocate for resources and change at the state and national levels. The 2022 National Strategy to Support Family Caregivers was the result of an unprecedented collaboration involving many agencies, organizations, and individuals in both government and the private sector — and stakeholders have organized advocacy efforts around it. There is also international momentum.



This work is creating a movement — partnerships that erase old boundaries where we work together to make sure that all types of caregivers and people receiving care can get what they need and the respect they deserve. This report highlights some of the progress we have made together — and the real changes we are making as a result. With that progress to motivate us and with these accomplishments as a foundation, we can — and must — continue this critical work to support family caregivers.

Alison Barkoff

Senior official performing the duties of the Administrator and Assistant Secretary for Aging Administration for Community Living
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About This Report

With the release of the [2022 National Strategy to Support Family Caregivers](#), Congress and the nation received the first-ever comprehensive, cross-sector approach to improving support for the family caregivers who provide the overwhelming majority of long-term care in the United States. Developed jointly by the [RAISE Family Caregiving Advisory Council](#) and the [Advisory Council to Support Grandparents Raising Grandchildren](#), established by the [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act](#) and the [Supporting Grandparents Raising Grandchildren \(SGRG\) Act](#), respectively, the 2022 National Strategy reflected extensive input from family caregivers, the people they support, federal agencies, and other stakeholders.

The strategy describes the most pressing needs as identified by family caregivers and the people they support — and provides a framework for a whole-of-society approach to begin to meet those needs. In addition, the strategy includes nearly 500 specific actions to ensure family caregivers have the resources they need to maintain their own health, well-being, and financial security while providing crucial support for others. More than two-thirds of those actions represent concrete, near-term commitments from 15 federal agencies; the remaining 150 actions could be implemented by states, communities, and the private sector. (Note: While the federal actions are significant, they are constrained by the RAISE Family Caregivers Act requirement that they be “within scope of existing programs.” Therefore, the federal actions within the strategy were limited to activities possible under existing budgets, programs, and authorities.)

This report focuses on federal achievements in support of implementing the strategy, including progress toward completing the initial 350 commitments. It also describes nearly 40 new commitments made by federal agencies since the release of the strategy.

Future reports and updates to the strategy will cover topics such as:

- New and emerging policy considerations impacting family caregivers and the people they support
- New recommendations for actions for all sectors to implement
- Analysis of the impact of the strategy



Background

Supporting Family Caregivers: Addressing a Critical – and Growing – Public Health Issue

The need for a robust, coordinated approach to supporting family caregivers has never been greater. Each year, at least 53 million people¹ provide informal, usually unpaid, care and support to older adults and people of all ages with disabilities, including people with mental health conditions and people with lifelong complex medical conditions. In addition, at least 2 million grandparents – and an unknown number of other relative caregivers – carry the responsibility for caring for children whose parents are unable to do so. The number of family caregivers is increasing rapidly due to growing populations of older adults and people with disabilities; the long-standing shortage of direct care workers, which reached crisis proportions during the pandemic and has continued; the continuing opioid crisis and other issues that are creating thousands of new “grandfamilies” each year; the lack of affordable, accessible child care for children with disabilities; and a variety of other factors.

Caregiving includes a wide variety of tasks to meet the individual needs of the person receiving support. Family caregivers routinely perform tasks such as housekeeping, transportation, and financial management, but the care they provide also can include intense and complex care requiring training and support to perform safely and effectively. They also supervise paid workers, coordinate services, and advocate for the people they support. Family caregivers most often provide support to help people live in their own homes and communities rather than in nursing homes and other institutions. However, it also can include support provided to older people and people with disabilities who live in institutional settings.

Family caregiving can be rewarding and personally satisfying, but it often comes at a significant personal cost to the caregiver. When family caregivers do not have sufficient training, support, and opportunities for rest and self-care – as far too many do not – their own health, well-being, and quality of life can suffer. Their financial future can also be put at risk. When family caregivers can no longer provide support, the people they care for often are left with no choices except to move to nursing homes or other institutional facilities or to foster care. These alternatives generally result in poorer outcomes at far greater costs – typically borne by taxpayers. Improving support to family caregivers is, therefore, an urgent public health and economic issue.



Who are “family caregivers”?

The RAISE Family Caregivers Act defined “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 condition, disability or functional limitation.” In its initial report to Congress, the RAISE Family Caregiving Advisory Council expanded the definition to include unpaid caregivers of all ages.

In its 2021 report to Congress, the Advisory Council to Support Grandparents Raising Grandchildren defined “kin and/or grandparent caregiver” to refer to any grandparent or relative who has primary responsibility for children whose parents cannot care for them.

In the 2022 National Strategy to Support Family Caregivers and this report, “family caregivers” include anyone meeting either definition.

Family caregivers include people of all ages, from youth to grandparents; people with and without disabilities; people providing care from a distance; and people meeting a wide variety of needs, such as supporting people with intellectual and developmental disabilities (I/DD) across the lifespan, caring for people with serious and/or progressive illnesses like dementia and cancer, and assisting with daily tasks that can be challenging for older people and people with disabilities. They include people of all education and socioeconomic levels, genders, races and ethnicities, and cultures, including tribal communities, and they have a wide variety of needs. Interventions to support them must be equally diverse and flexible enough to meet those needs.

Establishing a Framework for Action: 2022 National Strategy to Support Family Caregivers

The 2022 National Strategy to Support Family Caregivers marked an important milestone in our national efforts to address the longstanding need for a comprehensive system of family caregiver support. This first-of-its-kind roadmap represented an unprecedented collaboration between a broad cross-section of the federal government and the private sector. The report is the product of comprehensive analysis and input from 15 federal agencies and more than 150 organizations representing a range of stakeholders from across the United States.



The strategy is built upon more than two decades of incremental progress toward improving support for family caregivers by the federal government, including the development of a range of programs and services for family caregivers across the age and disability spectrum.

Based on the fundamental principle that each family caregiver deserves and needs to be recognized, assisted, included, supported, and engaged, the strategy sought to:

- Align federal, state, tribal, local, and other stakeholder responses to a set of goals and outcomes informed by thoughtful recommendations
- Foster collaborations within and across stakeholder groups
- Optimize existing family caregiver support efforts by reducing redundancy, improving information sharing, and incorporating best practices systemwide
- Prioritize efforts to advance equity for unserved and underserved populations of caregivers
- Ensure that all efforts to uplift caregivers are person- and family-centered, trauma-informed, and culturally competent

The strategy was developed as a framework to empower communities, agencies, and other stakeholder groups to select actions for implementation based on community and family caregiver needs and preferences (and those of the people receiving support) and in consideration of existing supports already in place, resource constraints, and other factors.

The strategy will be updated regularly based on the ongoing input of family caregivers and the people they support; the continued work of the advisory councils; communities, states and tribes, and federal agencies that are developing, implementing, and adapting policies and programs to support family caregivers; and other stakeholders. The strategy explicitly defines itself as the first of an ongoing series of steps toward creating a more cohesive and organized national system for supporting family caregivers.

Structure of the Strategy

The National Strategy consists of multiple components, each of which can stand on its own but, when taken together, present a comprehensive vision for better recognizing and supporting family caregivers. The National Strategy's four components include:

- [2022 National Strategy to Support Family Caregivers](#) — An overview and description of key issues, as well as the strategy's five goals and intended outcomes within each. The goals are:

- ◆ **Goal 1:** Increase awareness of and outreach to family caregivers
- ◆ **Goal 2:** Advance partnerships and engagement with family caregivers
- ◆ **Goal 3:** Strengthen services and supports for family caregivers
- ◆ **Goal 4:** Ensure financial and workplace security for family caregivers
- ◆ **Goal 5:** Expand data, research, and evidence-based practices to support family caregivers

The strategy emphasized the importance of a “whole of society” approach, making clear that achieving that vision cannot rely exclusively on federal actions (or on actions by states, communities, or any other single sector). Rather, it will require continued collaboration across all levels of government and across all sectors, including health systems and providers, human services networks, public and private sector entities, communities of faith, philanthropy, school and education systems, child welfare systems, etc. working together to bring the strategy to life.

- [Federal Actions](#) — Nearly 350 commitments to specific actions by 15 federal agencies. These actions are largely centered on increasing awareness and outreach, strengthening services and supports, and expanding data and research efforts. (To learn more, see the [slides from the September 2023 joint meeting](#) of the advisory councils in which the LeadingAge LTSS Center at the University of Massachusetts Boston presented the results of their analysis of the federal actions.) The federal actions contained in the strategy are significant but somewhat constrained by the RAISE Family Caregivers Act requirement that they be “within scope of existing programs.” Therefore, the federal actions within the strategy are limited to activities possible under existing budgets, programs, and authorities.
- [Actions for States, Communities, and Others](#) — More than 150 actions that can be adopted by state and local governments, service providers, and other stakeholders. Many complement the federal actions and offer ideas for how to better collaborate with other agencies and organizations, coordinate outreach, enhance program development and administration, and more effectively target family caregivers with available resources at more levels.
- [First Principles: Cross-Cutting Considerations for Family Caregiver Support](#) — Describes the four key principles that must be reflected in all efforts to improve support to family caregivers. These include:
 - ◆ **Person- and family-centered approaches:** As the nation continues to build a system to support family caregivers, it is important that the needs of family caregivers and the people they assist are the focus of every initiative and intervention, not the needs of systems or providers. In addition, it is critical that family caregivers define their needs themselves with the people they assist.

- ◆ **Trauma and its impact:** The experience of trauma in the lives of caregivers and the people they support, regardless of when it occurred, has an impact on the caregiving journey in ways that must be proactively addressed.
- ◆ **Diversity, equity, inclusion, and accessibility:** The difficulties and impacts of caregiving are not equally distributed. Caregivers who represent unserved, underserved, and/or marginalized communities frequently experience greater physical, emotional, and financial challenges associated with caregiving.
- ◆ **The direct care workforce crisis:** Low wages, lack of benefits, limited opportunities for career growth, and other factors have resulted in a long-standing shortage of these critical professionals, which reached crisis levels during the COVID-19 pandemic. As a result, more than three-quarters of service providers report declining new participants and more than half have cut services — which both increases demands on family caregivers and reduces their access to respite care and other services. Development and retention of a robust, well-trained, and fairly compensated direct care workforce is crucial to ensuring family caregivers and those they support have access to reliable, trusted, and affordable paid supports and assistance when and where they need it.

Learn about ACL's [Direct Care Workforce Strategies Center](#), which provides resources, technical assistance, and training to state systems, providers, and stakeholders to improve workforce recruitment, training, and retention.

Stakeholder Engagement

The initial strategy was developed based on extensive stakeholder input, and continual feedback has shaped the ongoing work of the advisory councils and will inform future updates. Nearly 600 comments were received during a 60-day formal [public comment period in late 2022](#). In addition to giving general feedback on the strategy, respondents answered questions about possible additions and which elements they believed were most critical. Responses were received from a wide range of stakeholders, including family caregiving advocates (46%), family caregivers (44%), caregiver support service providers (37%), researchers (13%), and representatives of state and/or local governments (9%).² (Many respondents provided multiple comments.) Most comments were directed toward Goal 3, which focuses on services and supports for caregivers. Goal 4, which focuses on improving financial and workplace security, received the second-highest number of comments.



[Analysis of the comments](#) by partners at the LTSS Center at the University of Massachusetts Boston found that stakeholders considered all components of the strategy to be critical, but some were viewed as particularly important. These include the direct care workforce crisis, the availability and accessibility of caregiving training and supports, the availability and accessibility of respite services, and the need for some form of caregiver compensation.

Notably, many of the needs identified as most crucial by respondents (and by both advisory councils) would require Congressional action to be put into place. These include:

- Establishment of a federal tax credit for family caregivers
- Implementation of immigration reform to expand the direct care workforce
- Expansion of family-friendly benefits for federal employee caregivers (including access to paid leave) so that the federal government can become a model for employers nationally
- Expansion of funding to support implementation of the strategy, including creating federal grants for states, tribes, and territories to implement recommendations, such as wage increases for direct care workers
- Ensuring that tribal organizations are eligible for funding under programs supporting older adults and caregivers

Respondents also called for accountability in tracking the strategy's implementation and impact, with the role of the federal government (and, specifically, ACL) seen as critical to this process. These responses proposed numerous ideas for how to achieve accountability, including publication of information about federal actions to support implementation of the strategy. This report represents a first step toward that recommendation by the advisory councils, ACL, and federal partners.

Overall, public comments indicated broad support and enthusiasm for the strategy and the approach it takes to calling on all parts of society to engage and act on behalf of family caregivers.

In addition, throughout 2022 and 2023, ACL leaders spoke at over 40 convenings across the U.S. about the strategy's development and implementation, including the importance of public/private partnerships, the necessity for broad stakeholder engagement, and ensuring services for family caregivers and the people they support can reach underserved populations.



Impact of the Strategy: Direct Action and a Catalyst for Change

In the 18 months since its release, the strategy has served as a catalyst, both within the U.S. and abroad, for improving support for family caregivers. Nearly all of the initial 350 federal commitments in the initial strategy have been completed or are in progress.

In addition, the strategy has helped drive:

- **New programs and initiatives:** Federal agencies have added nearly 40 new actions to the federal commitments, bringing the total to just under 400. In addition, as a result of the strategy and the ongoing work of the advisory councils, federal agencies have developed and launched a number of new programs and initiatives.
 - ◆ For example, in 2023, ACL [awarded \\$20 million in new grants](#) to foster advancements in two caregiver support programs authorized by the Older Americans Act.
- **Improved efficiency and coordination:** The process of developing the strategy improved federal agencies' visibility into each other's work, which has created opportunities for improved coordination of resources, as well as the development of joint initiatives.

Key Federal Accomplishments

Nearly all of the 350 federal actions in the 2022 National Strategy to Support Family Caregivers have been completed or are in process, and federal agencies have added 40 new commitments. Key accomplishments include:

Goal 1: Implementation, Outreach, and Awareness

- An executive order from the White House with more than 50 directives to federal agencies to make investments to support care workers, family caregivers, and the people they support
- \$20 million in new funding for technical assistance to support implementation of the strategy
- Federal guidance to states to ensure that new state plans on aging reflect and advance the actions in the strategy



Goal 2: Engagement of Caregivers

- Dissemination of new family caregiving training through the Health Resources and Services Administration's (HRSA) Geriatrics Workforce Enhancement Program and its 2,700 partnerships with academic, primary care, and community-based organizations
- A new rule to equalize foster care payments for family caregivers

Goal 3: Services and Support

- Medicare payment for family caregiver training, issued in the final 2024 Physician Fee Schedule
- A new Guiding an Improved Dementia Experience (GUIDE) model available to Medicare beneficiaries and their family caregivers
- Development of a curriculum with SAMHSA and FEMA to provide peer support for caregivers during emergency situations
- New engagement of AmeriCorps Seniors volunteers to provide respite to caregivers
- New VA clinical resource hubs to deliver psychotherapy directly to caregivers, reducing travel time
- ACL's new Direct Care Workforce Strategies Center, which provides resources, technical assistance, and training to state systems, providers, and stakeholders to improve workforce recruitment, training, and retention

Goal 4: Financial Security

- A new Office of Disability Employment Policy [report about paid leave](#) that includes information about state programs
- A new VA program to provide financial and legal support for family caregivers participating in the VA Program of Comprehensive Assistance for Caregivers

Goal 5: Data and Research

- New family caregiver data collection by the CDC, with 9 revised questions about caregiving in the BRFSS and the addition of one caregiving question on the National Health Interview Survey (NHIS)
- \$5.4 million in new NIA funding for research that can lead to the development and assessment of measures to capture the experiences of family caregiving for people with Alzheimer's disease and related dementias

A detailed summary of the status of federal actions begins on page 18.

- **International Engagement and Collaboration:** The strategy and the work of federal agencies to implement it have opened doors to increased collaboration with international partners, allowing the U.S. to share information and lessons learned with other countries and to accelerate the development of best practices that could be adopted in the U.S. For example:
 - ◆ In March 2023, leaders from ACL and the U.S. Department of State participated in the United Nations’ annual interactive debate on the rights of persons with disabilities and a companion event co-sponsored by the U.S. and Argentina that focused specifically on the caregiving infrastructure. The leaders shared U.S. actions to develop disability-inclusive support and care systems that respect human rights and ongoing steps to transform service models to facilitate inclusion, choice, and personalized supports for people with disabilities and their families.
 - ◆ Also in March 2023, ACL leadership spoke at the Organization of American States as part of their commemoration of World Down Syndrome Day. [Read Alison Barkoff’s submitted statement](#) and [watch a video of her remarks](#).
 - ◆ In November 2023, Alison Barkoff delivered a keynote address at the [Canadian Caregiving Summit](#), convened by the Canadian Centre for Caregiving Excellence (CCCE). This event, the first of its kind for Canada, brought together people with lived experience, leaders, policymakers, and researchers across the aging and disability communities to build the foundation of a national caregiving strategy. The CCCE sought input from the U.S. based on our experience developing the 2022 National Strategy to Support Family Caregivers.

Learning From Our International Partners

Many other countries have long recognized the critical importance of supporting family caregivers, including providing services, supports, and other benefits to their citizens and developing and implementing a national strategy or framework for addressing their needs. For example:

- Belgium, France, Germany, and the Netherlands have adopted policies to promote flexible arrangements for all workers — regardless of their caregiving responsibilities. Some, such as Germany, also allow for payment and training of family caregivers.
- In 2023, the United Kingdom published its first ever [National Kinship Care Strategy](#) and offers workplace flexibilities specifically developed for family caregivers.



- Spain and France are making progress toward implementing policies to reconcile caregiving with employment through initiatives such as unpaid leave for caregiving tasks.
- Ireland, Slovakia, Luxemburg, and Canada offer cash payments either directly to the caregiver or to the person receiving support to purchase home care — including in some cases, care provided by relatives.
- In 2010, Australia passed the Carer Recognition Act which acknowledges the significant role of caregivers and the importance of ensuring their needs are considered in policies, programs, and services that affect them. The Australian government further solidified this vision when it released its National Carer Strategy 2011.

Continued Momentum: Support for National Implementation

Supporting family caregivers is an issue that affects — and unites — us all. All branches and levels of government, advocates and stakeholder groups representing a wide variety of interests and industries, family caregivers and the people they support, and more have come together to support the ongoing development and implementation of the strategy. For example:

- On April 18, 2023, President Biden signed the [Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers](#), a comprehensive set of more than 50 directives to federal agencies to support high-quality, affordable child care, preschool, and long-term care. The executive order directed the government to take action to make care more affordable for American families, support family caregivers, boost compensation and improve job quality for care workers, and expand care options.

The executive order includes actions to improve support for the nation's family caregivers, who provide a [substantial portion](#) of the long-term support to older adults and people with disabilities. It also directs actions to expand the availability of home and community-based services, including those funded by Medicaid and the Department of Veterans Affairs. Many of these actions are tied directly to the strategy.

The executive order created new momentum for ACL's work to strengthen the care infrastructure that helps people with disabilities and older adults live and fully participate in their communities, including ACL's work leading the implementation of the strategy and strengthening and expanding the [direct care workforce](#), the partnership with the Veterans Health Administration on the [Veteran-Directed Care](#) program, and more.

- The [Act on RAISE campaign](#), led by the National Alliance for Caregiving, is bringing together stakeholders across the caregiving continuum (aging groups, patient advocacy groups, disability groups, and caregiving groups) to drive the implementation of the actions in the strategy.
- Several significant federal regulations have included provisions that will improve support to family caregivers. For example:
 - ◆ On February 6, 2024, ACL released updated [Older Americans Act regulations](#), the first comprehensive update in more than 30 years. The rule aligns regulations to the current statute, addresses issues that have emerged since the last update, and clarifies a number of requirements. The new regulations provide guidance for the implementation of the National Family Caregiver Support Program and the Native American Caregiver Support Program, which were authorized since the last update. For the first time, the aging network that provides the services authorized under the Older Americans Act has regulations in place that address the National Family Caregiver Support program, providing uniformity in the services caregivers across the nation receive through Title III-E of the Older Americans Act. Additionally, ACL is providing guidance to states to ensure that new state plans on aging reflect and advance the principles of the strategy.
 - ◆ On April 22, 2024, the Centers for Medicare & Medicaid Services released the [Ensuring Access to Medicaid Services final rule](#). The Access Rule will strengthen the home and community-based services (HCBS) that make community living possible for millions of people. It includes important new requirements related to the direct care workforce, health and safety protections, access to HCBS, quality measures, and state accountability and transparency. By improving access to HCBS, the Access Rule will both help decrease demands on family caregivers and improve caregivers' ability to access the services they need themselves.
 - ◆ The [Medicare 2024 Physician Fee Schedule](#) established new billing codes for caregiver training services, allowing eligible practitioners to bill Medicare for providing training and education to caregivers of beneficiaries with chronic illnesses or disabilities.



Implementing the National Strategy to Support Family Caregivers: Progress on Federal Actions

The 2022 National Strategy to Support Family Caregivers includes nearly 350 commitments from 15 federal agencies for specific near-term actions to support the strategy's vision. These commitments were the result of a six-month process in which the federal agencies inventoried and identified ways in which they could leverage or modify their existing programs to more explicitly support family caregiving without requiring additional legal authorities or funding.

Nearly all of the federal actions included in the initial strategy are completed or in progress. In addition, since the publication of the initial strategy, federal agencies have committed to nearly 40 more actions.

This report provides information about agency progress on these actions in three ways:

1. **Federal Progress Snapshot:** The table below provides a tally of the number of actions committed to by each agency and how many actions are currently in each of several status categories.
2. **Agency Highlights:** On pages 21 through 46, you will find highlights of key accomplishments reported by each agency. These reflect progress from October 2022 through September 2023. In this section, you also will find additional commitments made by each agency since the initial strategy was released in 2022.
3. **Detailed Reports by Agency:** Appendix A includes agency-by-agency spreadsheets reflecting progress on each federal action in the initial strategy as reported in two surveys by ACL — the first in March 2023 and the second in September 2023. Agencies were asked to report on the status of their actions by indicating whether each was completed, in progress, or modified in some way. (Modifications may include adjustments to actions made in response to changes in scheduling priorities, funding, policy, or an expansion in scope or refinement of an action and the identification of different/new cross-linkages with other goals and actions.) In addition, several agencies reported that new programming opportunities allowed them to initiate actions that had not been included in the initial strategy; those also are reflected in the spreadsheets.



Snapshot: Progress on Federal Actions³

Department/Agency	Total actions	Complete	In Process	To Be Modified	Modified	Not Yet Started	Cancelled
Department of Health and Human Services	269	99	145	10	3	9	3
Administration for Children & Families	14	7	6	N/A	N/A	N/A	1
Administration for Community Living	98	46	44	2	N/A	5	1
Assistant Secretary for Planning and Evaluation	6	4	1	N/A	N/A	N/A	1
Centers for Disease Control and Prevention	42	7	30	4	1	N/A	N/A
Centers for Medicare & Medicaid Services	29	18	11	N/A	N/A	N/A	N/A
Health Resources and Services Administration	23	4	19	N/A	N/A	N/A	N/A
Indian Health Service	15	5	10	N/A	N/A	N/A	N/A
National Institutes of Health	2	N/A	2	N/A	N/A	N/A	N/A
National Institute on Aging	21	5	12	2	2	N/A	N/A
National Institute on Minority Health and Disparities	1	N/A	1	N/A	N/A	N/A	N/A
National Institute of Nursing Research	1	1	N/A	N/A	N/A	N/A	N/A
Substance Abuse and Mental Health Services Administration	17	2	9	2	N/A	4	N/A
AmeriCorps	19	3	10	N/A	1	3	2
Consumer Financial Protection Bureau	27	10	16	1	N/A	N/A	N/A
Department of Labor	42	14	24	N/A	2	2	N/A
Department of Education	5	1	2	N/A	N/A	2	N/A
FEMA	1	1	N/A	N/A	N/A	N/A	N/A
Department of Veterans Affairs	21	15	6	N/A	N/A	N/A	N/A



New Momentum for Interagency Collaboration

President Biden's April 2023 executive order, [Increasing Access to High-Quality Care and Supporting Caregivers](#), directed the secretary of labor and the Secretary of Health and Human Services to “conduct a review to identify gaps in knowledge about the home- and community-based workforce serving people with disabilities and older adults; identify and evaluate existing data sources; and identify opportunities to expand analyses, supplement data, or launch new efforts to provide important data on the home- and community-based care workforce and ensure equity for people with disabilities and older adults.”

Filling these gaps and identifying these opportunities requires engagement from many entities, including the federal government, states, the research community, nonprofits, and private sector businesses, who all have an important role to play in building this data infrastructure.

In response to the president's call, the U.S. Department of Health and Human Services (HHS) and the Department of Labor (DOL) established the [Home and Community-Based Services Federal Opportunities Regarding Workforce and Research Data \(HCBS FORWARD\)](#) workgroup in May 2023. Over the following year, the workgroup, led by the Office of the Assistant Secretary for Planning and Evaluation at HHS, met to identify key policy questions on the HCBS workforce to establish data priorities, analyze existing data sources on this workforce, and identify ways to fill critical gaps in knowledge.

On April 25, 2024, HHS and DOL jointly released an issue brief, [Improving Data on the Workforce Delivering Home and Community-Based Services](#), which summarizes the HCBS FORWARD workgroup's recommendations to federal and state agencies, nonprofit organizations, and research institutions to improve data infrastructure and information on the HCBS workforce.

Implementing these recommendations will bolster the data infrastructure needed to answer key questions about the HCBS workforce and drive data-informed policy decisions to improve the quality of and access to HCBS for the millions of Americans who are receiving or need these services.



Agency Highlights

U.S. Department of Health and Human Services (HHS)

Administration for Community Living (ACL)

The Administration for Community Living (ACL) maximizes the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers. It funds services and supports — provided primarily by networks of community-based organizations — and invests in research, education, and innovation so that older adults and people of all ages with disabilities can participate fully in their communities. ACL leads the implementation of the RAISE Family Caregivers Act and the SGRG Act and facilitates the work of the two advisory councils. ACL committed to approximately 100 actions in support of the 2022 National Strategy to Support Family Caregivers. The following are some highlights of ACL's efforts.

In 2022, ACL launched its [Direct Care Workforce \(DCW\) Strategies Center](#) to provide resources, technical assistance, and training to state systems, providers, and stakeholders to improve workforce recruitment, training, and retention. In February 2024, the DCW Strategies Center launched its website, and [HHS announced several new initiatives, technical assistance opportunities, and resources from ACL's DCW Strategies Center](#). To date, 20 states have been selected to participate in two separate technical assistance programs that will help participating states better recruit, train, and retain direct care workers who provide home and community-based services (HCBS) for older adults and people with disabilities. The announcement also recognized 26 stakeholders, primarily direct care professionals and people who receive HCBS, who were selected to serve as members of the center's inaugural advisory committee. That committee will help guide the center's work and recent federal efforts to strengthen the nation's capacity to support community living.

In September 2023 and February 2024, ACL announced the availability of \$20 million in funding to establish a new National Caregiver Support Collaborative (NCSC). Through the NCSC, ACL will work with five national grantees to foster advancements in two programs authorized by the Older Americans Act: the [National Family Caregiver Support Program](#) and the [Native American Caregiver Support Program](#). Each grantee will focus on one goal within the strategy:

- **Community Catalyst**
 - ◆ Goal 1: Increase awareness of and outreach to family caregivers
- **Regents of the University of California, San Francisco**
 - ◆ Goal 2: Advance partnerships and engagement with family caregivers



- **USAgings**
 - ◆ Goal 3: Strengthen services and supports for family caregivers

- **University of Southern California**
 - ◆ Goal 4: Strengthening financial and workplace security for family caregivers

- **National Alliance for Caregiving**
 - ◆ Goal 5: Expand data, research, and evidence-based practices to support family caregivers

ACL's Administration on Disabilities (AoD) continues to fund the Bridging the Aging and Disabilities Networks Initiative, which supports a community of practice (CoP) that involves 17 states. Participating states receive supports and resources to strengthen their aging and disability networks and improve their ability to help individuals with intellectual and developmental disabilities (I/DD) and their families plan for the future using person-centered and culturally competent approaches. The initiative involves state and local level partners across the aging and disability sectors (such as state units on aging, state DD agencies, and disability and aging community-based organizations) that work together to develop strategies to improve access to aging services for individuals with I/DD and their family caregivers. ACL's AoD received additional funding from the Administration on Aging (AoA) to expand resources to effectively bridge the aging and disability networks.

ACL's Center for Regional Operations (CRO) presented five caregiving workshops at the 2023 Title VI National Conference, which addresses services for American Indian, Alaska Native, and Native Hawaiian populations offered through the Older Americans Act (OAA). The CRO also provided specific information and guidance to states on how to incorporate and address the strategy in their updated state plans on aging. In late 2023, in coordination with the regional CMS Office of Program Operations & Local Engagement, CRO began planning for a series of HHS bi-regional listening sessions in 2024 with state unit on aging leaders and coordinators of the Title III-E National Family Caregiver Support Program.

ACL's Office of Elder Justice and Adult Protective Services (OEJAPS) identified grandfamilies as a priority population for the next round of Legal Assistance Enhancement Program Grants.

Funded by ACL's National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), the National Rehabilitation Research and Training Center (RRTC) on Family Support at the University of Pittsburgh began implementing its goal-setting procedures for family caregivers of older adults enrolled in the Community Aging in Place, Advancing Better Living for Elders (CAPABLE) program.



NIDILRR also launched a research project to compare the effectiveness of two established interventions for caregivers of people with acquired brain injuries. The results will help determine whether group or individual interventions led by peers or clinicians are most effective. Primary and secondary data analysis were underway as of the end of 2023.

ACL's Office of Performance and Evaluation began piloting the addition of a new question in the 2023 National Survey of OAA Participants. The question will ask recipients of OAA services (such as congregate or home-delivered meals or transportation services) whether they are also caregivers.

Following the release of the strategy, new RAISE and SGRG councils convened in July 2023 to continue the work of implementing their respective legislative mandates:

- Established by the RAISE Family Caregivers Act, the [RAISE Council](#) is charged with providing recommendations on effective models of family caregiving and support to family caregivers as well as improving coordination across federal government programs.
- Established by the SGRG Act, the [SGRG Council](#) identifies, promotes, and disseminates information, resources, and best practices to help older relatives meet the needs of children in their care while maintaining their own well-being.

Additional Actions

Since the release of the initial strategy in 2022, ACL committed to — and began implementing — the following seven additional actions:

Outcome 1.1: Americans are educated about and understand the experience of family caregiving.

- ACL's Office of Nutrition and Health Promotion Programs (ONHPP), within the Administration on Aging (AoA), will engage caregivers in evidence-based health promotion and disease prevention programs to achieve the goal of educating about the experience of family caregiving, including chronic disease self-management education (CDSME), falls prevention, and mental health.
- ACL's Office of Nutrition and Health Promotion Programs (ONHPP), within the Administration on Aging (AoA), will provide education and resources to achieve the goal of promoting caregiver health and well-being through ACL's National Chronic Disease Self-Management Education (CDSME), Falls Prevention, and Nutrition and Aging resource centers.

- The National Chronic Disease Self-Management Education (CDSME) Resource Center and the National Falls Prevention Resource Center at the National Council on Aging (NCOA) will provide support to state and community-based organizations for the implementation, expansion, and sustainability of evidence-based health promotion programs for older adults, adults with disabilities, and caregivers. The [NCOA Caregiver Hub](#) includes resources for professionals in the aging and public health field to reach caregivers and for caregivers to access directly online. For example, resources contained in the Caregiver Hub include Benefits Check-Up, Prescription Assistance for Caregivers, Benefits for Caregivers, National Family Caregivers Month toolkit, Helping Seniors with Budgeting: Practical Tips for Caregivers, Unconditional: Mental Health of Caregivers Subject of Powerful Documentary, and Avoiding Scams and Fraud for Caregivers.

Outcome 3.1: Person- and family-centered, trauma-informed, and culturally appropriate caregiver services and supports are accessible for all family caregivers.

- In Fiscal Year 2024, ACL’s Office of Nutrition and Health Promotion Programs (ONHPP), within the Administration on Aging (AoA), will publish a [blog](#) through the National Chronic Disease Self-Management Education (CDSME) Resource Center entitled “Engaging Caregivers in Evidence-Based Programs.”
- In FY25, ACL’s Office of Nutrition and Health Promotion Programs (ONHPP), within the Administration on Aging (AoA), will conduct a webinar to help achieve the goal of educating attendees on person- and family-centered, culturally relevant, and trauma-informed information, services, and support.
- In FY24, ACL’s Office of Nutrition and Health Promotion Programs (ONHPP), within the Administration on Aging (AoA), will fund a grant to include a caregiver focus when addressing programs and services for adults with serious mental illness.

Outcome 5.3: Promising and evidence-informed practices are promoted, translated, and disseminated to support family caregivers in the delivery of health care and social services.

- ACL’s National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) will fund the Rehabilitation Research and Training Center (RRTC) on Family Support at the University of Pittsburgh to host a national State of the Science on Family Caregiving Research Conference in September 2024 to meet the goal of increasing promotion, translation, and dissemination of promising and evidence-supported practices to support family caregivers in the delivery of health care and long-term services and supports (LTSS).



Administration for Children & Families (ACF)

The Administration for Children & Families (ACF) promotes the economic and social well-being of families, children, individuals, and communities and provides leadership and resources for the compassionate, effective delivery of human services. It administers programs that provide financial assistance, family support, child care, child welfare, and adoption services. While child care and similar supports are outside the scope of the strategy, ACF committed to 14 actions to support caregivers. The following are some highlights of those efforts.

Most notably, on September 28, 2023, ACF issued a [final rule](#) that allows Title IV-E child welfare agencies to use separate licensing or approval standards for foster family homes of relatives or kin and non-relative foster family homes. The new rule also requires equal foster care maintenance payments (FCMP) in these homes. This rule became effective on November 27, 2023.

ACF's Children's Bureau has created online resources and videos about kinship caregiving. The [It's All Relative Guide](#) talks about the experiences of kinship caregivers, mainly grandparents. ACF has funded kinship navigator programs in all states and 12 Title IV-E tribes.

ACF's Children's Bureau continues to oversee the *Family Connection Grant: Building the Evidence for Kinship Navigator Programs*. Kinship Navigator (KN) programs assist kinship caregivers in learning about, finding, and using programs and services to meet the needs of the children and youth they are raising and their own needs. The goal of this project is to implement a rigorous local evaluation designed to demonstrate significant findings on the effectiveness of the KN program on select target outcomes, including child safety, stability in their living situation, child or adult well-being, access to services, referrals to services, and/or satisfaction with services. The first-year award amount is up to \$600,000, with a project period of up to 36 months.

The Children's Bureau holds quarterly webinars with the states that highlight best practices. Additionally, the Children's Bureau funded a cooperative agreement to develop a national training and development curriculum for foster and adoptive parents and kinship families, including a free online resource about building resilience in kinship caregivers.

Centers for Disease Control and Prevention (CDC)

The Centers for Disease Control and Prevention (CDC) works to protect public health and safety by preventing and responding to diseases, whether chronic or acute, curable or preventable, caused by human error or deliberate attack. It conducts research, provides information on health threats, and supports public health initiatives and emergency response efforts. CDC has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.



CDC committed to updating the Healthy Brain Initiative five-year roadmap, which establishes national priorities for public health regarding brain health, including actions around dementia caregivers. The roadmap addresses four domains that align with the strategy:

- Strengthen partnerships and policy
- Measure, evaluate, and use data
- Build and retain a diverse and skilled workforce
- Engage and educate the public

A set of 24 actions helps guide public health departments and their partners as they consider how to advance brain health in communities and provide support for caregivers.

Other CDC actions relate to collecting and analyzing data and improving current data systems, including the Behavioral Risk Factor Surveillance System (BRFSS), which collects data about behaviors that affect health. CDC undertook a structured approach to reduce the burden of responding to national surveys, specifically by reducing the number of questions.

CDC awarded a cooperative agreement to the Alzheimer’s Association, and one activity under this award was to assist in revising the BRFSS caregiving module. The revised section has nine questions that align with CDC’s goals for caregiving data and will help serve public health activities. CDC will begin administration of the new questions in 2024. CDC has also arranged to add a caregiving question to the 2025 National Health Interview Survey (NHIS).

Additional Actions

Since the release of the initial strategy in 2022, CDC committed to — and began implementing — the following three additional actions:

Outcome 1.4: Family caregiving — and caregivers — are embedded in federal, state, territorial, tribal, and local planning.

- CDC will update the *Healthy Brain Initiative Road Map for Indian Country* by 2024, including changing the title to Road Map for American Indian and Alaska Native Peoples. This road map establishes national public health priorities for brain health among Native American people.
- CDC will support the implementation and evaluation of the Healthy Brain Initiative’s Road Map Series, which includes actions regarding dementia caregivers, by the 43 Building Our Largest Dementia (BOLD) Infrastructure Program award recipients by 2028.



- CDC will support the development of or revisions to Alzheimer’s disease and related dementias (ADRD) strategic plans for jurisdictions, which include support for dementia caregivers, by state and jurisdictional public health departments of BOLD Program award recipients by 2028.

Centers for Medicare & Medicaid Services (CMS)

The Centers for Medicare & Medicaid Services (CMS) is the federal agency that provides health coverage to more than 160 million people through Medicare, Medicaid, the Children’s Health Insurance Program, and the Health Insurance Marketplace. CMS works in partnership with the entire health care community to improve quality, equity, and outcomes across the health care system.

CMS has committed to multiple actions in support of the National Strategy to Support Family Caregivers. The following are some highlights of those efforts.

CMS released [four action briefs to support state Medicaid and partner agencies](#) that design and deliver services to support adults with intellectual and developmental disabilities (I/DD), as well as their aging parents and caregivers.

Multiple CMS presentations and all-state trainings were held covering information about available methods states can use to operationalize payment for family caregivers in their Medicaid programs and how to continue this program flexibility beyond the COVID-19 Public Health Emergency (PHE).

The White House, in collaboration with CMS, [released a national overview](#) highlighting American Rescue Plan (ARP) section 9817 investments in home and community-based services (HCBS) across the nation with updates to the section [9817 Infographic on Medicaid.gov](#). These updates include descriptions of state initiatives to increase access to and availability of caregiver supports.

Additional Actions

Since the release of the initial strategy in 2022, CMS committed to — and began implementing — the following 15 additional actions:

Outcome 1.2: Caregiver self-identification and knowledge of services is enhanced.

- CMS will consider including information about the hospice complaint process for beneficiary awareness in a future “Medicare & You” handbook, and Medicare Hospice Benefits booklet. The handbook already includes general information about what to do if you have a complaint about a Medicare provider. CMS has also included details on how to submit a quality of care complaint in the [Medicare Hospice Benefits booklet](#).

- CMS continues implementation of the Consolidated Appropriations Act of 2021 and will soon post hospice survey outcomes on Hospice Care Compare, to inform beneficiaries and families during their selection of a hospice.
- Annually, CMS updates the CMS Hospice Handbook to further identify resources for family and caregivers and will consider future updates as additional resources are developed.
- Hospice Conditions of Participation (COPs) at 42 CFR Part 418 strongly support the education and inclusion of the caregiver and acknowledge the importance of the caregiver's role; hospice care focuses not only on the beneficiary, but their family and caregivers as well.
- CMS will conduct a scoping literature review to identify evidence-based interventions that engage family caregivers in post-acute care. The results will help the CMS Office of Minority Health develop post-acute care outreach and education materials for family caregivers by 2026.

Outcome 1.4: Family caregiving — and caregivers — are embedded in state, territorial, tribal, and local planning.

- In 2023, CMS' Medicaid Benefits and Health Programs Group (MBHPG) published a Center for Medicaid and CHIP Services (CMCS) [Informational Bulletin](#) reminding states of tools to better connect direct support workers to individuals receiving Medicaid-covered home and community-based services (HCBS). This guidance focuses on building and maintaining worker registries (worker management platforms that make qualified health workers easier to find) and notes significant federal funding available to help states build these registries through the American Rescue Plan (ARP).

Outcome 2.1: Family caregivers are recognized as essential partners in the care teams of the person(s) to whom they are providing support.

- On September 25, 2023, CMS supported engagement with family caregivers by issuing [CMS memorandum QSO 23-23-NHs](#), which reinforced that civil money penalty (CMP) funds may be used for projects by not-for-profit resident advocacy organizations that:
 - ◆ Assist in the development of new independent family councils
 - ◆ Assist resident and family councils in effective advocacy on their family member's behalf
 - ◆ Develop materials and training sessions for resident and family councils on state implementation of new federal or state legislation

- On July 1, 2024, CMS launched the Guiding an Improved Dementia Experience (GUIDE) Model through the Innovation Center with 390 participating organizations building dementia care programs. This eight-year voluntary model, which is being offered nationwide and focuses on dementia care management, aims to improve the quality of life for people living with dementia, reduce strain on their unpaid caregivers, and enable people living with dementia to remain in their homes and communities. The GUIDE Model will test whether providing an alternative payment methodology for participating dementia care programs to deliver a package of care management and coordination, caregiver education and support, and GUIDE Respite Services to traditional Medicare beneficiaries with dementia and their caregivers reduces expenditures while preserving or enhancing quality of care.

Outcome 2.2: Where appropriate, identifying services and supports for caregivers consistently starts with a review of family caregiver strengths, needs, and preferences using evidence-based assessments.

- As part of the [Guiding an Improved Dementia Experience \(GUIDE\) Model](#), participating providers will be required to assess caregivers of beneficiaries living with dementia on the caregiver’s knowledge, needs, and social supports, as well as well-being, stress level, and other challenges. In addition, participating providers must assess caregivers annually on the caregiver’s level of strain and report this information to CMS. Providers will be measured and receive payment adjustments based in part on their ability to reduce caregiver strain through the model. After the assessment, providers are required to include recommendations for the caregiver’s education and support services in the beneficiary’s care plan.
- In the 2024 Physician Fee Schedule, CMS proposed and finalized [policy changes to pay for principal illness navigation services](#), including care navigation services for individuals with high-risk conditions, including dementia. Identifying and referring the patient and caregiver (if applicable) to appropriate supportive services can be part of this navigation.

Outcome 2.3: Where appropriate, family caregivers are included and considered in the development of care recipients’ plans of care across a range of settings and circumstances.

- In the 2024 Physician Fee Schedule, CMS proposed and finalized [policy changes to pay for principal illness navigation services](#), which are care navigation services for individuals with high-risk conditions, including dementia. Identifying and referring the patient and caregiver (if applicable) to appropriate supportive services can be part of this navigation.



Outcome 2.5: The education curricula of professions who will potentially work with family caregivers include specific topics and coursework designed to ensure they have the skills to do so effectively.

- The CMS Innovation Center’s [Guiding an Improved Dementia Experience \(GUIDE\) Model](#) requires participating providers to ensure its care navigators receive training on specific topics, including knowledge of caregiver strain and supports (e.g., peer-to-peer support, support group, 1:1 support), in-home caregiver training, and importance of caregiver education. Further, the CMS Innovation Center’s Learning and Diffusion Group will provide participants in the GUIDE Model with peer-to-peer education and case study reviews to enhance skills in supporting caregivers of people living with dementia.

Outcome 3.1: Person- and family-centered, trauma-informed, and culturally appropriate caregiver services and supports are accessible for all family caregivers.

- The CMS Innovation Center’s [Guiding an Improved Dementia Experience \(GUIDE\) Model](#) requires participants to administer a caregiver support program, which must include (i) caregiver skills training on a variety of topics to meet the caregiver’s specific needs; (ii) information on the beneficiary’s dementia diagnosis in the primary language spoken by the beneficiary and caregiver; (iii) support group services for caregivers; and (iv) ad hoc one-on-one support calls with the caregiver to address caregiving issues as they arise.

Outcome 3.2: Family caregivers can obtain respite services that meet their unique needs.

- The CMS Innovation Center’s [Guiding an Improved Dementia Experience \(GUIDE\) Model](#) allows participants to provide in-home respite services, and participants will have the option to provide respite services at adult day centers or facilities that can provide 24-hour care. The CMS Innovation Center will pay participants up to \$2,500 (geographically adjusted and annually updated) per beneficiary per year.



Outcome 3.3: A range of evidence-based education, counseling, and peer support services are available to caregivers.

- CMS finalized policy changes for Medicare payments under the Physician Fee Schedule (PFS), effective January 1, 2024. Beginning in January, Medicare began paying practitioners to train caregivers to support people with certain diseases or illnesses in carrying out a treatment plan. Medicare pays for these services when furnished by a physician or a non-physician practitioner (nurse practitioner, clinical nurse specialist, certified nurse-midwife, physician assistant, and clinical psychologist) or therapist (physical therapist, occupational therapist, or speech-language pathologist) as part of the individualized treatment plan or therapy plan of care. (Also supports outcome 3.8.)

Outcome 3.5: Family caregivers have innovative tools and technology to assist them in their roles.

- CMS will continue to ensure that the [Medicare.gov Care Compare website](#) gives beneficiaries, families, and caregivers valuable information about the providers they may need to access to meet the needs of their loved ones, such as information about nursing home providers.

Health Resources and Services Administration (HRSA)

The mission of the Health Resources and Services Administration (HRSA) is to improve health outcomes and achieve health equity through access to quality services, a skilled health workforce, and innovative, high-value programs. HRSA has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.

HRSA provides [caregiving training](#) for caregivers of persons living with dementia and for health care providers. Part one of the caregiving training addresses self-care for family caregivers, common behaviors associated with dementia, and how to choose assisted living/nursing home care. Part two addresses working with family caregivers as allies, including caregivers in shared decision-making and caring for family caregivers. HRSA's Geriatrics Workforce Enhancement Program and Geriatrics Academic Career Awards program (GWEP and GACA) are disseminating this training broadly through their approximately 2,700 partnerships with academia, primary care sites and delivery systems, and community-based organizations.



HRSA includes a caregiver on its [Advisory Committee on Interdisciplinary, Community-Based Linkages](#) who provides advice and recommendations to the Secretary of HHS and Congress on policy and program development for education and training programs related to primary care, geriatrics, and mental health. HRSA's geriatric programs are required by statute to provide training to family caregivers, and adding a caregiver to the advisory committee was an important step to ensuring that training reflects the needs of caregivers.

Additional Actions

Since the release of the initial strategy in 2022, HRSA committed to — and began implementing — the following two additional actions:

Outcome 2.1: Family caregivers are recognized as essential partners in the care teams of the person(s) to whom they are providing support.

- HRSA's Geriatrics Workforce Enhancement Program (GWEP) and Geriatrics Academic Career Awards (GACA) grant recipients educate caregivers to be members of the interprofessional health care team.
- HRSA's [caregiving curriculum teaches caregivers](#) how to be part of the interprofessional health care team. The curriculum also teaches health care providers how to include caregivers on the interprofessional health care team.

Indian Health Service (IHS)

The Indian Health Service (IHS) provides care and services to 2.8 million American Indian and Alaska Native people who are members of 574 federally recognized tribes. The system includes IHS-run facilities, tribally-run facilities, and urban Indian health organizations, with much of the funding going to care and services provided and managed by tribes. Collectively, the three parts of the IHS system employ tens of thousands of employees, two-thirds of whom are members of the direct care workforce. IHS has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.

IHS conducted a successful social media campaign for National Family Caregivers Month in November 2022 and continued to raise awareness about caregiving through social media posts and other outreach materials. For example, IHS created specific social media content to define the term “caregiver” because the term often doesn't resonate in tribal communities, which can reduce the effectiveness of outreach efforts. In September 2023, IHS shared posters about National Grandparents Day and National Family Caregivers Month. The agency is onboarding a new communications contractor to help with observances and engagement. The agency has also incorporated caregiving resources on its webpages.



IHS funded two new Extension for Community Healthcare Outcomes (ECHO) series in 2023. These programs expand access to specialty training and are designed for clinical and community staff. They include case-based learning and didactic training. One ECHO, led by council member Dr. Neil Henderson (Choctaw Nation), is focused on caregiving, with 30-50 participants each month. IHS worked with three CDC Centers of Excellence that are addressing dementia, including the Public Health Center of Excellence on Dementia Caregiving at the University of Minnesota.

IHS awarded four Alzheimer's disease and related dementias cooperative agreements in 2022, totaling \$1.2 million, and eight new awards in September 2023. All grantees must address caregiving as part of their efforts to build comprehensive models of dementia care.

In 2024, IHS plans to host an informal workgroup to study caregiving interventions that focus on people living with dementia. The group will get feedback from tribal participants on priorities for caregiving services and supports in local tribal communities.

Another big priority for IHS is to figure out how to incorporate caregiving data elements into the electronic health records (EHR) system. The agency also sees a need for interventions and training, as well as plain language materials for both paid and nonpaid caregivers that are developed by and with tribal communities to ensure they reach caregivers in the workforce and the community.

National Institutes of Health (NIH)/National Institute on Aging (NIA)

As one of the 27 institutes and centers that make up the National Institutes of Health (NIH), the National Institute on Aging (NIA) leads the federal government in conducting and supporting research on aging and the health and well-being of older people. NIA conducts genetic, biological, clinical, behavioral, social, and economic research on aging. NIA also fosters the development of researchers and clinical scientists focused on aging and disseminates information about aging and research advances to the public, health care professionals, and scientific communities. NIA has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.

As of September 2023, NIA had completed five action items from the strategy, and 14 were in progress. A few actions were modified along the way to incorporate new programs, to add a cross-link in one case, and to reassign an action to a different objective in another. Many of the actions implemented relate to increasing awareness and outreach to family caregivers, as well as advancing and strengthening supports for family caregivers. NIA also has funded several projects aimed at building the national infrastructure to support the expansion of evidence-based data.

NIA issued two companion requests for applications (RFA) to solicit research on methods and measures for family caregiving for people with Alzheimer's, with the purpose of supporting research that can lead to the development of methods and measures that capture diverse experiences in how diverse groups (e.g., individuals who are sexual and gender minorities, racial/ethnic minorities, living alone, and/or immigrants) experience informal caregiving for people living with Alzheimer's disease.⁴ NIA has funded nine new grant awards through these funding announcements, with an investment of \$4 million per year in five-year awards, plus \$1.4 million per year in two-year awards.⁵

This research will help capture the growing numbers of adults who are aging without spouses or biological children. For many of these adults, blended families and families of choice provide informal care, and these “kinlike” relationships (e.g., stepfamilies, chosen families) not captured in standard survey measures may play a significant role in caretaking.

NIA has also recently launched new initiatives directly related to caregiving and the detection and prevention of abuse and neglect among older adults at risk for cognitive impairment or other dementias. Four grants were funded in 2022 in response to [RFA-AG-22-024](#): Primary Care-Based Screening and Intervention Development for Prevention of Abuse in Older and Vulnerable Adults in the Context of Alzheimer's Disease and Related Dementias (R61/R33 Clinical Trial Required). This NOFO was reissued in 2023 as [RFA-AG-24-048](#), but no applications were selected for funding.

Additional Actions

Since the release of the initial strategy in 2022, NIA committed to — and began implementing — the following three additional actions:

Outcome 4.1: Family caregivers can provide care without negative impacts on their near- and long-term financial health.

- On August 28, 2023, NIA issued two relevant Notice of Funding Opportunities (NOFOs). The first, [RFA-AG-24-031: Consortium for Economic Research on AD/ADRD Prevention, Treatment, and Care](#) (R01 Clinical Trial Optional), aimed to build a consortium of research projects that aim to advance economic research on Alzheimer's disease (AD) and Alzheimer's disease-related dementias (ADRD) by examining the development and diffusion of treatment/care innovations, payment and treatment models for care and care access for people living with dementia and their caregivers, and economic factors influencing disease progression. The second NOFO, [RFA-AG-24-030: Consortium for Economic Research on AD/ADRD Prevention, Treatment, and Care Coordinating Center](#) (U54 Clinical Trial Optional), solicited applications that propose to develop a coordinating center to support this consortium. These NOFOs directly address NIH's [AD/ADRD research](#)



[implementation milestones 1.P, 13.P, 13.M, and 13.N](#). Applications for both Notices of Funding Opportunities were due on December 30, 2023, and were considered for funding in NIA's May 2024 National Advisory Council on Aging meeting. An award was issued for the coordinating center in 2024, and funding is imminent for numerous research grants that will be participating in this consortium.

Outcome 5.1: A national infrastructure will exist to support the collection of population-based data, using standardized wording of the definition of family caregiving, and standardized wording of questions that address the core characteristics of the family caregiving experience.

- NIA issued [RFA-AG-24-037: Limited Competition: National Health and Aging Trends \(NHATS\) and National Study of Caregiving \(NSOC\)](#) (U01 Clinical Trial Not Allowed), which expired on September 30, 2023. Applications will be reviewed and considered for funding in FY24.

Office of the Assistant Secretary for Planning and Evaluation (ASPE)

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of HHS for policy development and budget decisions related to health, disability, human services, data, and science. ASPE leads special initiatives, manages cross-department strategic planning, and coordinates the department's evaluation, research, and demonstration activities. ASPE has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.

Six research projects focused on family caregivers have been completed as of March 2023, and the agency is working on publishing the results. For example, one project under Goal 5 expanded data research and evidence-based practices to support family caregivers. The project, called "Supporting Families and Caregivers of Adults with Behavioral Health Disorders," examined the unique needs of family caregivers of adults with behavioral health disorders or substance use disorders. The project included a technical expert panel with researchers, a caregiving support program provider, public health leaders, and people with experience in behavioral health caregiving. The project is complete, and the report is in clearance for release in 2024.



Substance Abuse and Mental Health Services Administration (SAMHSA)

The Substance Abuse and Mental Health Services Administration (SAMHSA) leads federal public health and service delivery efforts that promote mental health, prevent substance misuse, and foster recovery while ensuring equitable access and better outcomes. It provides funding, data, and resources to improve prevention, harm reduction, treatment, and recovery services for individuals with mental and substance use disorders. SAMHSA has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.

SAMHSA has increased access to meaningful and culturally relevant information services and supports for family caregivers and kinship families. In 2023, SAMHSA's Office of Recovery hosted a Family and Caregiver Technical Expert Panel, which recognized the stigma and challenges many families face when raising or taking care of a family member with mental health and/or substance use conditions. SAMHSA provides Statewide Family Network grants to enhance the capacity of statewide mental health family-controlled organizations to engage with family members/primary caregivers who are raising children, youth, and young adults with serious emotional disturbance and/or co-occurring disorders. SAMHSA and the Administration for Children & Families (ACF) collaborated on a webinar about substance use and its effects on child welfare. Two additional webinars focused on issues of caregivers when substance use is an issue and providing care for a child with a serious emotional disturbance.

SAMHSA is partnering with the U.S. Department of Veterans Affairs (VA) to address suicide prevention, the caregiver crisis, and how states and communities can better support military communities and their veteran caregivers. SAMHSA is also developing a curriculum to provide peer support for caregivers during emergency situations.

Other Federal Departments and Agencies

AmeriCorps

AmeriCorps engages individuals in public service work to help communities address critical needs in education, public safety, health, and the environment. It provides funding and support to service programs and encourages civic engagement and volunteerism. AmeriCorps has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.

AmeriCorps has about 1,100 grantees that engage older adults in volunteerism. The agency works to make sure that grantees understand the needs of caregivers and that organizations working with caregivers know about grant opportunities at AmeriCorps Seniors.



AmeriCorps' Senior Companion Program and RSVP Program are the main programs at AmeriCorps that support caregivers. Senior Companion volunteers focus on supporting independent living and providing respite for older adults and their caregivers. RSVP volunteers provide educational activities in their communities and provide respite and benefits navigation services to caregivers. Many volunteers are also caregivers themselves.

The 2020 National Study of Caregiving indicated that 44% of family caregivers of adults provided support with health care and personal tasks, but only 17% used respite services, with only 4% of caregivers in rural areas using respite. COVID-19 further weakened the respite care workforce.

Working with the National Respite Coalition, AmeriCorps Seniors invested \$2.5 million to support a three-year pilot program to provide increased respite to caregivers and create a pathway to respite employment. The coalition will engage at least 200 AmeriCorps Seniors (ACS) volunteers to provide respite to caregivers across the age and disability spectrum in New York State. The AmeriCorps Seniors volunteers will address the shortage of respite care workers and support increased social support and improved capacity for independent living. The program will primarily serve individuals from rural and economically disadvantaged communities.

This project will implement the Respite Educational and Support Tools (REST) training model, which is an evidence-based intervention for in-home or group settings. Volunteers will also be trained through a Respite Care Provider Certificate program. Volunteers completing the program will receive certification and have access to a centralized respite care provider registry that connects caregivers with volunteers and paid respite providers. They will also receive follow-up technical assistance and additional training.

Information about caregiving and grant opportunities related to caregiving are shared in monthly newsletters that go out to all the grantees. Several programs are using AmeriCorps Seniors grants to build a respite care workforce through training and certification.

Consumer Financial Protection Bureau (CFPB)

The Consumer Financial Protection Bureau (CFPB) aims to ensure that banks, lenders, and other financial institutions treat consumers fairly. It protects people from unfair, deceptive, or abusive practices and acts against companies that break the law. The agency also provides consumers with information to help them make informed decisions. The CFPB has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.



The CFPB Office for Older Americans monitors unfair consumer practices that target older Americans and family caregivers. One example is attempts by nursing homes to have caregivers provide a personal guarantee of payment as a condition of admission. This is a violation of the Nursing Home Reform Act, and attempts to collect from caregivers may violate the Direct Collection Practices Act and the Fair Credit Reporting Act, both of which are regulated and enforced by CFPB.

CFPB has also acted to clarify the law surrounding caregiving and financial health, including [a report on medical debt](#), [a joint letter with CMS to debt collectors and nursing homes](#), and [a joint blog with ACL for long-term care ombudsmen](#).

CFPB continues to hold financial caregiving webinars for state health insurance counselors, legal services groups, elder justice networks, and others. This includes webinars based on the [Managing Someone Else's Money](#) financial caregiving resources for lay people who serve as agents under a power of attorney, guardians, conservators, trustees, or government fiduciaries.

CFPB continues to publicize its new factsheet for those early in the caregiving process, [Considering a financial caregiver? Know your options](#).

CFPB has incorporated Managing Someone Else's Money into its joint program with the Federal Deposit Insurance Corporation (FDIC), [Money Smart for Older Adults](#), thus expanding and enhancing its reach.

Additional Actions

Since the release of the initial strategy in 2022, CFPB has completed or committed to the following two additional actions:

- From April to September 2023, CFPB offered several webinars that included its Managing Someone Else's Money financial caregiving materials to refugee groups, LGBTQ+ groups, financial groups, service coordinators, and other government agencies to help serve underserved populations with culturally sensitive information.

Outcome 4.4: Long-term services and supports are more affordable, allowing family caregivers to reduce their out-of-pocket costs.

- CFPB is monitoring issues affecting the finances of people attempting to pay for long-term supports and services, with the goal of producing deliverables in the future.



U.S. Department of Education (ED)

The Department of Education (ED) promotes student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access. It administers federal financial aid, collects school data, and enforces federal educational laws regarding privacy and civil rights. ED has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.

ED provides information to all families relevant to their children's education. ED distributes newsletters and social media posts that spread the message about resources available through the federal government, and the agency's Office of Communication and Outreach amplifies messages that can help keep family caregivers, grandparents, and other relatives raising children informed about available services.

ED's Office of Elementary and Secondary Education funds statewide family engagement centers focused on skills that support family members' involvement in their children's education. Some, such as the [Ohio Statewide Family Engagement Center](#), have specific materials for grandfamilies and kinship families.

ED's Office of Special Education Programs addresses the needs of families of children with special education or special health care needs, including grandparents raising grandchildren, through its system of parent training and information centers. ED has centers in every state and territory, and community parent resource centers in underserved communities. The centers inform family caregivers about services available for their children and youth with disabilities and amplify the federal government's messages about family caregiving, grandfamilies, and kinship families through newsletters and social media posts directly to families. The community parent resource center in Virginia specifically focuses on foster and kinship/granfamilies.

U.S. Department of Labor (DOL)

The Department of Labor (DOL) fosters, promotes, and develops the welfare of America's wage earners, job seekers, and retirees — working to improve working conditions and advance opportunities for profitable employment. It oversees federal labor laws on occupational safety, wage standards, unemployment insurance benefits, and reemployment services. DOL has committed to several actions in support of the national strategy to support family caregivers. The following are some highlights of those efforts.

DOL's Office of Federal Contract Compliance Programs oversees contractors and subcontractors to the federal government to make sure they comply with laws and regulations, including antidiscrimination measures that combat gender-based stereotypes about caregiving responsibilities.



The Office of Disability Employment Policy (ODEP) is the only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities. ODEP has a new website about paid leave that includes information about state programs. DOL's [National Center on Leadership for the Employment and Economic Advancement of People with Disabilities \(LEAD\)](#) hosted a think tank and listening session on the shortage in the direct care workforce. The recommendations were shared with 18 different government agencies and [compiled into a report](#).

DOL's ODEP, the Office of the Assistant Secretary for Policy (OASP), and the Women's Bureau have been collaborating with HHS on improving data collection through the Home and Community Based Services (HCBS) FORWARD Workgroup formed in response to the president's [Executive Order \(EO\) on Increasing Access to High-Quality Care and Supporting Caregivers](#). The workgroup developed joint statements about the importance of having good data to guide investments in caregiving and published them in blogs on [November 1, 2023](#), and [November 22, 2023](#), in observance of National Family Caregivers Month. [The workgroup delivered recommendations in response to the EO in April 2024](#).

DOL's Women's Bureau is the only federal agency mandated to represent the needs of wage-earning women, and caregiving issues are an important focus. The Women's Bureau accomplishes this mission through a combination of research and policy analysis, grant-making, and education and outreach. For example, the Women's Bureau recently collaborated with the Urban Institute to estimate the lifetime costs of caregiving. Grandparents raising grandchildren are getting attention from the Women's Bureau as well.

As part of President Biden's [Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers](#), DOL is conducting research on wages for the direct care workforce and developing collaborations with HHS related to providers of home and community-based services.

Additional Actions

Since the release of the initial strategy in 2022, DOL committed to — and began implementing — the following 15 additional actions:

Outcome 1.1: Americans are educated about and understand the experience of family caregiving.

- The Women’s Bureau, in collaboration with the Chief Economist’s Office (CHECO), published an update to DOL research originally published in 2015 estimating the potential economic activity that would occur if women in the U.S. participated in the labor force at the same rate as women in comparable OECD countries that invest more in policies to support working caregivers.
- The Women’s Bureau will build upon its portfolio of products related to older women workers and their financial security. Most activity will revolve around data analysis. Products will analyze the gender wage gap for older women workers and older women, preparations for eventual retirement, and their financial security.
- The Women’s Bureau will implement another wave of the American Time Use Survey (ATUS) Leave and Jobs Flexibilities Module in 2024. Survey development and planning began in FY22 and, as with the last module, will allow for disaggregation by race and ethnicity to lend insight into demographic variance in access to and use of leave. The Women’s Bureau will, in consultation with the Office of Management and Budget (OMB) and the Bureau of Labor Statistics (BLS), finalize the ATUS Leave and Job Flexibilities Module questionnaire and training materials and begin data collection.

Outcome 2.5: The education curricula of professionals who will potentially work with family caregivers include specific topics and coursework designed to ensure they have the skills to do so effectively.

- ODEP’s Workforce Innovation and Opportunity Act (WIOA) Policy Development Center, Leadership for the Employment and Economic Advancement of Individuals with Disabilities (LEAD Center), will research and create a graphic tool showing lattices/ladders of possible career pathways for individuals in the direct support professional/caregiving field.

Outcome 3.9: An agile, flexible, and well-trained direct care workforce is available to partner with and support family caregivers.

- In FY24, the Women’s Bureau will continue to collaborate with HHS, the U.S. Department of the Treasury, and the Employment and Training Administration (ETA) to pursue strategies for raising wages for care workers.



- The Women’s Bureau, the Office of the Assistant Secretary for Policy (OASP), and the Chief Economist’s Office (CHECO) will collaborate on an analysis of early childhood and home care workers’ pay in comparison to the pay of other workers with similar levels of training and skill. In FY24, these entities will publish a research report and issue guidance to help states and localities conduct their own analyses of comparable pay rates for care workers in their respective jurisdictions.
- In partnership with the Wage and Hour Division, the Women’s Bureau created sample employment agreements for domestic workers who provide child and long-term care and developed an outreach and dissemination plan to encourage widespread use, including making the sample agreements available in 8 languages.
- The Women’s Bureau, in collaboration with the Office of the Assistant Secretary for Policy (OASP) and The Office of Disability Employment Policy (ODEP), participated in a DOL and HHS workgroup on direct care workforce data (“HCBS FORWARD”) to identify gaps in knowledge about the home and community-based workforce serving people with disabilities and older adults; identify and evaluate existing data sources; and identify opportunities to expand analyses and supplement data to provide important data on the home and community-based care workforce and ensure equity for people with disabilities and older adults.
- The Women’s Bureau continues to work with elected officials to support investments in rebuilding care infrastructure and strengthening the majority female workforce that performs this essential work. These investments are crucial to ensure the success of the national and local economies. The Bureau will provide technical assistance through the Good Jobs, Great Cities Academy to help cities.
- ODEPs WIOA Policy Development Center, the LEAD Center, will conduct research on existing direct support professional apprenticeship programs to identify critical information resulting from these programs, such as wages, timelines, areas of innovation, and other areas of interest.
- ODEPs WIOA Policy Development Center, the LEAD Center, will conduct research to determine the relevance of the National Service program to advancing availability of direct support professional/caregiving staff.

Outcome 4.1: Family caregivers can provide care without negative impacts on their near- and long-term financial health.

- Following the Chief Evaluation Office (CEO) release of the updated Worker PLUS model, the Women’s Bureau has worked with stakeholders in several states, academic groups, support state analysts, and presented a workshop at the biennial conference of the Work Family Research Network on using the simulator for modeling the use and cost of paid leave benefits. CEO has also provided new resources for using Worker PLUS, including videos on installing and running the simulator. The Women’s Bureau will convene state administrators of paid leave programs to discuss opportunities and challenges for program implementation and improvements.
- To create state-based momentum on paid leave, the Women’s Bureau will continue to:
 - ◆ Target states with existing paid family medical leave (PFML) laws to amplify stakeholder stories, including stakeholder engagement highlighting the impacts of the policy “before & after” the implementation of PFML policies.
 - ◆ Work through its regional offices to engage with local- and state-paid family and medical leave and paid sick days administrators and stakeholders to increase education about existing laws.
 - ◆ Advance the discussion on equity in access to paid family medical leave and paid sick and safe days through webinars, written products, and regional engagement, focused on lifting up success at the state and local level and identifying and disseminating promising practices at the national, state, and local levels.
- The Women’s Bureau and the Wage and Hour Division (WHD) will conduct outreach/education activities to help women know their rights under the Family Medical Leave Act (FMLA), as well as the Pregnant Workers Fairness Act, PUMP Act, other labor protections for nursing workers, and, where applicable, in concert with state and local paid family medical leave laws. The Women’s Bureau and WHD will create industry-specific programming and outreach specifically for women workers. In addition, the Bureau will work with local advocacy organizations to serve as trusted messengers about leave and accommodation rights to their constituents and convene leaders to serve as model coalitions around their state laws to other states.

- The Women’s Bureau executed a one-year contract with the Urban Institute titled “Understanding Equity in Paid Family and Medical Leave through Microsimulation Analysis.” The team will expand the analytical simulation tools and research available through governmental and non-governmental entities that are able to answer more questions about the costs and projected benefits of paid leave policies. This commissioned project will provide local, state, and federal policymakers, philanthropies, researchers, and advocates with data and analysis related to how paid family and medical programs interact with existing safety net programs; how paid leave might enhance their reach and impact; and what policy changes could mean for the broader economy and people’s economic security and well-being. Additionally, this work will include supplementary technical assistance in the appropriate use of those tools and interpretation of outputs to both state-based and federal entities.

Outcome 4.2: Family caregivers have access to employee-centered flexible workplace policies and practices that support work/life balance and professional performance when personal circumstances change.

- The Women’s Bureau will continue to work with the U.S. Department of Health and Human Services (HHS) and other U.S. Department of Labor (DOL) agencies to provide ongoing technical assistance to assist other federal agencies with expanding supportive services investments — including access to care — through infrastructure and related funding through FY2024. This work is a result of the President’s Care Executive Order.
- The Office of Personnel Management (OPM) issued a Report on the Use of the Federal Employee Paid Parental Leave Benefit (FEPLA) that examines the use of the new paid parental leave benefit for federal employees, including how many federal employees used the benefit, how many weeks of the allowed leave employees used, and what factors employees cited for taking less than the allowed amount of paid parental leave. DOL’s Chief Evaluation Office (CEO) and the Women’s Bureau continue to work with OPM on data sharing to extend the analysis for subsequent years and plan to obtain data to study the FEPLA’s impacts on retention and advancement in federal service.



Outcome 4.3: Family caregivers have access to and use of financial education and advance planning tools.

- The Women’s Bureau will continue to build upon its portfolio of products related to older women workers and their financial security. The work will include an examination of the asset development and net worth of older women workers, including women of color, in the wake of the pandemic. It will also include an analysis of the recent asset development, specifically through employment-based retirement savings and poverty rates of older women. Finally, the Bureau will highlight the changing profile of older women in the U.S. in terms of demographics and occupations and plans to explore the possibility of disseminating “know-your-rights” information sheets regarding issues that directly impact older women workers and their financial well-being.

U.S. Department of Veterans Affairs (VA)

The Department of Veterans Affairs (VA) provides essential services and support to veterans, their families and caregivers, and survivors. It aims to improve the quality of life for those who have served in the military by providing health care and other benefits, memorial services, and access to an array of education, housing, and employment services. The VA has committed to several actions in support of the national strategy to support caregivers. The following are some highlights of those efforts.

VA raises awareness and reaches out to caregivers in several important ways. A newsletter called Vet Resources goes out weekly to the listserv of over 13 million people. Occasionally, it covers resources available to caregivers. VA also maintains listservs specifically for caregivers.

VA conducts several training programs, some directed to the caregiver community specifically and some to the veteran community in general. The former includes training that helps individuals understand their changing role as caregivers; the latter focuses on practical “how-to” information for caregivers, such as how to change a bandage.

VA is strengthening services and supports for caregivers by expanding mental health services to caregivers of veterans through telehealth, which is often much more convenient for caregivers. To build on progress made in telehealth during the COVID-19 pandemic, VA has created clinical resource hubs to deliver psychotherapy by licensed professional counselors and psychologists directly to caregivers, reducing travel time. VA started with clinical resource hubs in three regions of the country and will be moving into several more by the end of this calendar year. The program has provided 500 visits to almost 120 caregivers.



VA has also partnered with the [Rosalynn Carter Institute for Caregivers](#) to develop an [emergency preparedness toolkit specifically designed for caregivers](#).

VA has also launched a program to provide financial and legal support for family caregivers participating in the VA Program of Comprehensive Assistance for Caregivers. Through the program, family caregivers can work with a legal or financial professional to help them in their caregiving journey.

Conclusion

The advisory councils applaud the remarkable progress made by the federal government in implementing the 2022 National Strategy to Support Family Caregivers in the short time since its release. The strategy has created a ripple effect at home and abroad, spurring interest from organizations, communities, states, and other nations that will continue to advance this important work. At the same time, there is much more work to be done, and the need continues to grow as more people, in a wide range of circumstances, require assistance from caregivers.

The advisory councils stand ready to continue the work with Congress to ensure every American can live and fully participate in their community. The strategy was an initial release and will evolve in response to the constantly shifting landscape of family caregiving policy, as well as the real-world needs of the nation's millions of family caregivers. By laying the groundwork for future reports and updates to the strategy, the advisory councils, with support from ACL and colleagues at the National Academy for State Health Policy (NASHP), are developing a powerful tool for sustainable long-term systemic change that will benefit all of society for generations to come.

About the Advisory Councils

The 2022 National Strategy to Support Family Caregivers is the result of three years of focused effort by two Congressionally mandated advisory councils: The RAISE Family Caregiving Advisory Council (RAISE Council) and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG Council).

The two advisory councils were formed in 2019 to explore and document the challenges faced by family caregivers and kin and grandparent caregivers, respectively. Each was charged with providing actionable recommendations for supporting their corresponding caregiving populations in a holistic way both now and in the future. In addition, the RAISE Family Caregivers Act directed the development of a family caregiving strategy.



In 2021, each advisory council delivered an initial report to Congress. The reports contained recommendations for increasing awareness and outreach, inclusion, and services; reducing the financial challenges faced by family caregivers; and improving data, research, and the use of evidence-informed approaches in the field. The reports also offered testimonials from family caregivers to help illustrate why it is imperative that the nation do more to support them. During this work, it became clear that family caregiving is a diverse activity that affects different people at various stages of life and requires a wide range of skills and competencies. Realizing that the best way to holistically support all family caregivers would be through a unified effort, the advisory councils collaborated to develop the strategy.

Advisory Council Actions

The RAISE Family Caregivers Act called for forming a family caregiving advisory council consisting of up to 15 voting non-federal members who reflect the diversity of family caregivers and people who receive support. The act required that the advisory council include at least one member from each of the following constituencies: caregivers; older adults who need long-term services and supports; individuals with disabilities; health care and social service providers; providers of long-term services and supports; employers; paraprofessional workers; state and local officials; accreditation bodies; and veterans. The resulting [RAISE Council](#), initially launched in 2019, also included representatives from 15 federal departments and agencies with a role in addressing family caregiving issues.

During their tenure from 2019-2022, the first RAISE Council met 11 times and accomplished the following:

- April 2020: Developed and released [a report summarizing progress made during the first year of the council's work](#)
- November 2020: Formulated and adopted [26 recommendations](#) aimed at establishing a national approach to addressing the needs of family caregivers of all ages and circumstances
- September 2021: Developed and released an [initial report to Congress](#), which built on the recommendations released the year before, outlined the challenges faced by family caregivers, and inventoried federal programs currently available to support them
- September 2022: In collaboration with the SGRG Council, developed and released the [2022 National Strategy to Support Family Caregivers](#), the first of its kind roadmap for the nation for improving the recognition and support of family caregivers



A second RAISE Council was sworn in on September 19, 2023. Their work has focused on planning for future updates to the strategy.

The Supporting Grandparents Raising Grandchildren (SGRG) Act

Passed in 2018, just a few months after the RAISE Family Caregivers Act, the SGRG Act established the SGRG Council. The first SGRG Council included five grandparents raising grandchildren and other relatives, and eight members chosen because of their professional expertise in grandfamilies and kinship families. In addition, 10 representatives of federal agencies served as non-voting members.

The first meeting of the full SGRG Council also took place in August 2019, and the group met five times via an online platform between then and September 2022. During that time, the group identified, developed, and distributed information, resources, and best practices to help grandparents and other relatives and non-relatives meet the needs of the children in their care and maintain their own physical and mental health and emotional well-being. Key accomplishments include:

- August 2020: Developed and released a [COVID-19/Emergency Preparedness Resource Guide for Kinship Families and Grandfamilies](#), which listed resources to help these families respond to emergencies, such as the COVID-19 Public Health Emergency.
- October 2020: Formulated and adopted [22 recommendations](#) to advance change and improve supports to kinship families and grandfamilies of all ages.
- November 2020: Developed and released a [Year One Progress Report](#) highlighting council activities since the passing of the SGRG Act, including member selection, subcommittees, key meetings, and plans for the initial report to Congress.
- November 2021:
 - ◆ Developed and released an [initial report to Congress](#) outlining the joys, challenges, gaps, and unmet needs of kin and grandparent caregivers. It also described federal programs available to assist and provided 22 recommendations for better supporting kinship families and grandfamilies.
 - ◆ Developed and released [Supporting Grandparents Raising Grandchildren: Resources for Consumers and Professionals](#), a list of resources and best practices for kinship families, grandfamilies, and the professionals who support them.

Throughout 2022, with support from ACL, the SGRG Council collaborated with the RAISE Council to develop and release the strategy.



A second SGRG Council was sworn in on September 19, 2023. Like the new RAISE Council, their work has focused on planning for future updates to the strategy.

Acknowledgments

Since implementation of the RAISE Family Caregivers Act began in 2019, ACL's work has been supported by a unique, invaluable collaboration with The John A. Hartford Foundation (JAHF), the National Academy for State Health Policy (NASHP), and NASHP's partners.

With funding from JAHF, NASHP and its partners provide a range of technical assistance and support to a variety of stakeholders, including through two websites, [the RAISE Act Family Caregiver Implementation and Technical Assistance Center](#) and [Support Caregiving](#). Other accomplishments include the following:

- NASHP, through its collaboration with the LTSS Leading Age Center at the University of Massachusetts-Boston and Community Catalyst, provided a comprehensive analysis of responses to an ACL-issued request for information that helped shape future public engagement leading up to the development of both the council's initial report to Congress and the strategy.
- To assist the RAISE Council in developing its recommendations, NASHP collected, analyzed, and synthesized approximately 800 recommendations from 27 key family caregiving reports written during the previous decade. Read NASHP's [Inventory of Key Family Caregiver Recommendations](#).
- NASHP commissioned a paper by the Center for Medicare Advocacy (CMA) that explores the role Medicare does — and could — play in supporting older and disabled beneficiaries and their caregivers. Read CMA's [Medicare and Family Caregivers Issue Brief](#).
- Given the pivotal role of states in implementing the principles and concepts within the strategy, NASHP developed a range of [state resources](#) designed to guide their efforts. Additionally, the TA Center developed a [State Policy Roadmap for Family Caregivers](#). Using the five goals of the strategy as a framework, the goal of this set of publications is to provide a roadmap for state officials to better understand the policy landscape for supporting family caregivers and to identify opportunities for innovation in their own states.



- NASHP's [Support Caregiving](#) website contains sector-specific guides for strategies and approaches they can use to better recognize and support family caregivers. Sectors for which guides are available include state units on aging, area agencies on aging, family caregivers, kinship/grandfamilies, employers, managed care plans, counties, respite providers, and others.

Endnotes

Note: Links or references to non-federal organizations do not imply an endorsement by the U.S. Department of Health and Human Services. Views expressed by such organizations are not necessarily those of HHS.

- 1 [AARP and National Alliance for Caregiving. Caregiving in the United States 2020. Washington, DC: AARP. May 2020.](#)
- 2 Total adds up to more than 100% because some respondents represent multiple roles.
- 3 This table reflects the status of federal actions as reported to ACL in September 2023.
- 4 [RFA-AG-23-022: Measures and Methods for Research on Family Caregivers for People Living with Alzheimer's Disease and Related Dementias \(AD/ADRD\) \(R01 Clinical Trial Not Allowed\) \(nih.gov\)](#) and, [RFA-AG-23-023: Measures and Methods for Research on Family Caregivers for People Living with Alzheimer's Disease and Related Dementias \(AD/ADRD\) \(R21 Clinical Trial Not Allowed\) \(nih.gov\)](#).
- 5 https://reporter.nih.gov/search/jV_WVzAWhUGc9G9Tox4krw/projects and https://reporter.nih.gov/search/UqzS-_fdwkmmgTsKsikap-g/projects.