

Supporting Family Caregivers: Progress Towards Implementation of the 2022 National Strategy

Wednesday, October 9, 2024

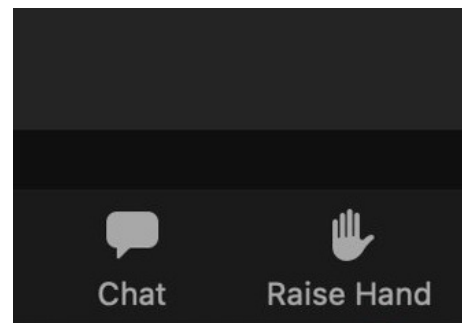




Event Logistics

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- **Chat box** to ask questions, make comments, and share resources
- **Raise hand** if you have a comment during the discussion portion



Please chat your name, organization, and location now!



About Long-Term Quality Alliance

- LTQA is a 501(c)3 membership organization aimed at improving outcomes and quality of life for people who need LTSS, and their families.
- LTQA advances person- and family-centered, integrated long-term services and supports (LTSS) through research, education, and advocacy.

For more information:



www.ltqa.org



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LONG-TERM QUALITY ALLIANCE



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[VNS Health](#)
[Volunteers of America National Services \(VOA\)](#)



Our Speakers



Scott Bane

**The John A.
Hartford
Foundation**



Greg Link

**Administration for
Community Living**



**Wendy Fox-
Grage**

**National Academy
for State Health
Policy**



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Foundation



LTQA Webinar:
*2022 National Strategy to Support Family
Caregivers*



October 9, 2024

Scott Bane, JD, MPA
Senior Program Officer
The John A. Hartford Foundation

Overview

- About The John A. Hartford Foundation
- Why we support family caregiving
- About the National Strategy to Support Family Caregivers
- Other family caregiving and related initiatives
- What you can do





The
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Foundation

A private philanthropy
based in New York City,
established by family
owners of the A&P
grocery chain in 1929



DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

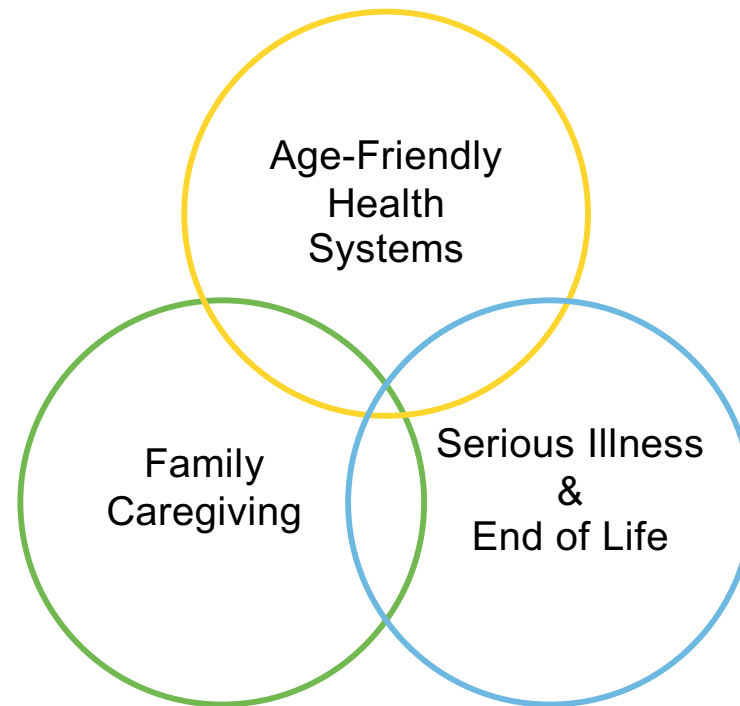


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Mission & Priorities

DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

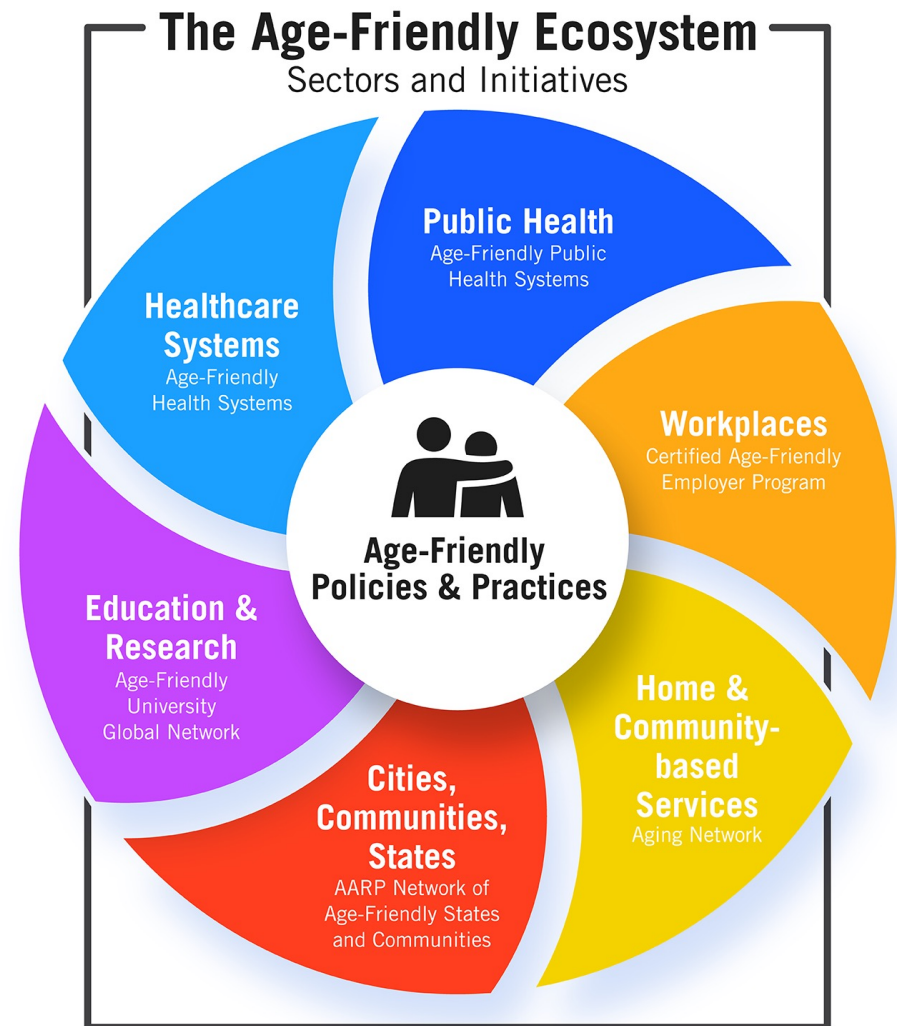
PRIORITY AREAS



DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

We all need an age-friendly society

- Longevity is greatest success story of last century
- As we age, we can make vital contributions and power up communities – with support
- A just society requires us to make all sectors **age-friendly**



Family Caregivers: the Backbone of Care in the U.S.

Many people will be a family caregiver and need a family caregiver in their lifetime

- 53 million people provide assistance to support the health, quality of life and independence of someone close to them
- 1 in 6 individuals is a family caregiver, and > 2/3 of people will need assistance with tasks as they age



Our Family Caregiving Funding Priorities

Our grantmaking will:

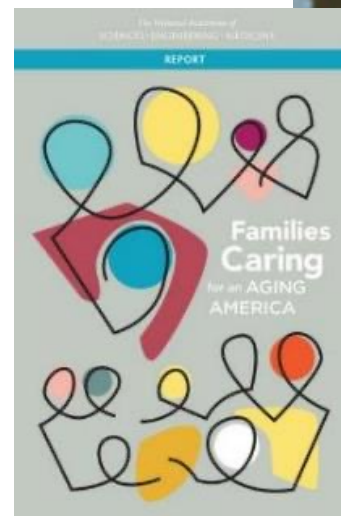
- Improve the ability of health systems and providers to identify, assess, and support family caregivers
- Raise awareness among policymakers, health system leaders, funders, and the public to drive change
- Create large-scale change in partnership with national efforts



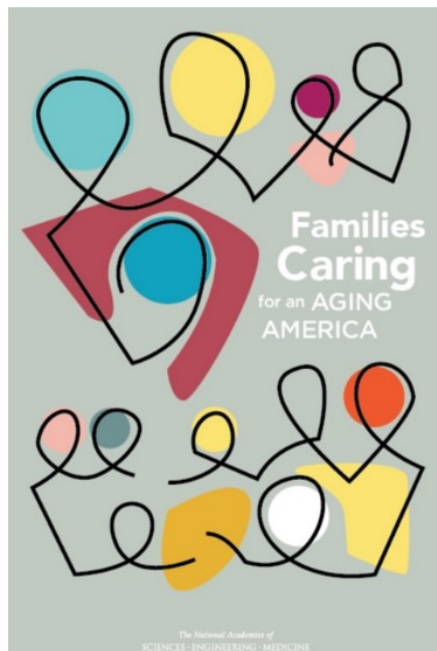
Families Caring for an Aging America (2016)

- Focus needs to be on person- and family-centered care
- Support of family caregivers needs to be an integral part of the nation's responsibility for caring for older adults
- 4 recommendations, one of which calls for a **national family caregiver strategy**

<https://nam.edu/families-caring-for-an-aging-america>



From Families Caring for an Aging America to RAISE



National Academies of Sciences, Engineering, and Medicine



DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

RAISE Act Initial Report to Congress (2021)



The Council of caregivers and experts developed recommendations under 5 goals:

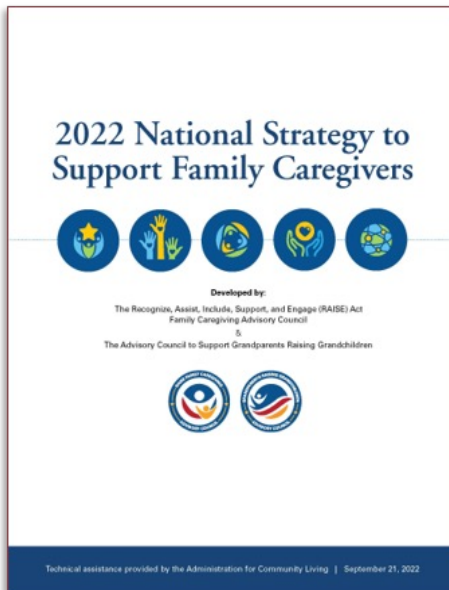
- 1) Expand **awareness, outreach and education** for family caregivers
- 2) Engage family caregivers as partners in delivery of **health care and LTSS**
- 3) Improve **access to services and supports** for family caregivers
- 4) Ensure **financial and employment security** for family caregivers
- 5) Generate **Research, Data, and Evidence-Informed Practices**

Available now:
**RAISE Family
Caregivers Act
Initial Report
to Congress**
September 2021



<https://acl.gov/RAISE/report>

The National Strategy – A Whole-of-Society Approach to Support Caregivers (2022)



2022 National Strategy to Support Family Caregivers - An overview and description of the strategy's goals and intended outcomes

Federal Actions - Nearly 350 commitments of 15 federal agencies to implement the strategy

Actions for States, Communities, and Others - More than 150 actions others can take

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



A Public-Private Collaboration to RAISE Up Family Caregivers



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DEDICATED TO IMPROVING THE CARE OF OLDER ADULTS

JAHF Support for RAISE in Partnership with ACL/NASHP



Funded grant to the National Academy for State Health Policy (2019) to:

1. Provide robust resources and technical supports to the RAISE Act Advisory Council and its subcommittees
2. Engage core partners and experts in the work
3. Develop family caregiving resources for state and federal policymakers and other stakeholders
4. Facilitate uptake and implementation of Council recommendations at the state level



National Campaign: Action Toward Implementation of Strategy



JAHF funded National Alliance for Caregiving to catalyze policy action and federal-level coordination:

- Engaging caregiver/patient advocacy groups, health systems, state-level coalitions
- Tracking implementation progress on federal commitments to ensure transparency and accountability
- Educating federal and state policymakers about opportunities to better support caregivers



ActOnRAISE.org



The Family Caregiver and Direct Care Worker Initiative



JAHF funded PHI and NAC to better integrate support for both direct care workers and family caregivers:

- Identifying and mapping regulations, training/technology needs, funding mechanisms that affect interconnected relationship
- Will present recommendations to educate federal and select state policymakers
- Launched Together in Care initiative



[TogetherInCare.org](https://www.togetherincare.org)

Philanthropy Has An Important Role



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Grantmakers in Aging: Family Caregiving Funders Community

- > 40 funders of varying sizes, types and geographies
- Shared commitment to supporting caregivers through innovative programs and policies
- Action Guide for Funders

Family Caregiving Funders Community

An Initiative of  GRANTMAKERS
IN AGING



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- Serious illness & end-of-life care





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Thank You!

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The National Strategy to Support Family Caregivers: A Roadmap for Change

LTQA Webinar

Greg Link, MA

Director, Office of Supportive and Caregiver Services
Administration for Community Living

October 9, 2024



Legislative Milestones in Family Caregiver Support

- Legislative actions

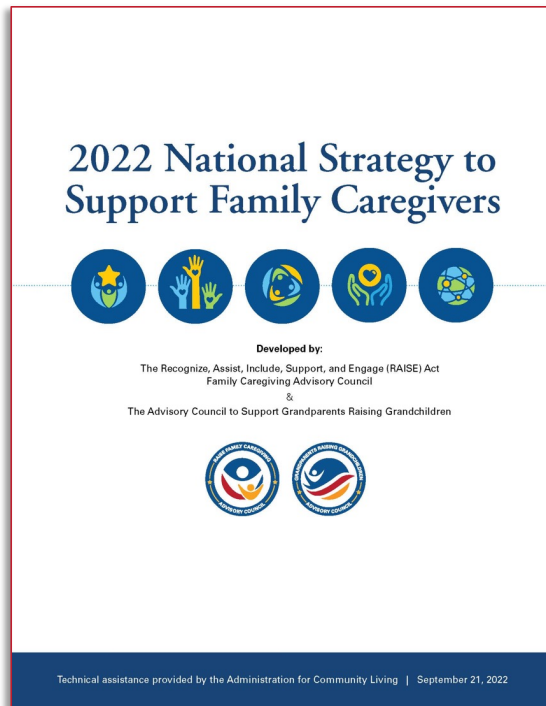
- National Family Caregiver Support Program/Native American Caregiver Support Program (2000)
- Lifespan Respite Program (2006)
- VA Caregiver Support Program (2010)
- RAISE Family Caregivers Act (2018)
- Family First Prevention Services Act (2018)
- Supporting Grandparents Raising Grandchildren Act (2018)
- National Technical Assistance Center on Kinship and Grandfamilies (2021)



The RAISE Act: Nuts & Bolts

- Became law: Jan 22, 2018
- Three key components:
 - Family Caregiving Advisory Council
 - Initial Report to Congress
 - National Family Caregiving Strategy

One Strategy | Four Components



[2022 National Strategy to Support Family Caregivers](#) - An overview and description of the strategy's goals and intended outcomes

[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

[Federal Actions](#) - Nearly 350 actions that 15 federal agencies will take in the near term to begin to implement the strategy.

[Actions for States, Communities, and Others](#) - More than 150 actions others can take.

The National Strategy to Support Family Caregivers

Five priority areas for action:

- 1) Awareness and outreach
- 2) Engagement of family caregivers as partners in healthcare and long-term services and supports
- 3) Services and supports for family caregivers
- 4) Financial and workplace security
- 5) Research, data, and evidence-informed practices

Cross-Cutting Themes & Considerations

- Placing the person and family at the center of all interactions
- Addressing trauma and its impact on families
- Advancing racial equity and support for family caregivers in underserved communities
- Understanding the implications of the direct care workforce

A “Whole of Society” Approach is Needed

- States, tribes, county governments, and communities – “the Aging Services Network”
- Community-based providers of long-term services and supports
- Child welfare agencies
- Health care systems
- Business leaders and employers
- Communities of faith/faith-based organizations
- National, state, regional and local philanthropic organizations and funders
- Academic institutions and researchers
- Advocates, family caregivers, care recipients, you, me, anyone!



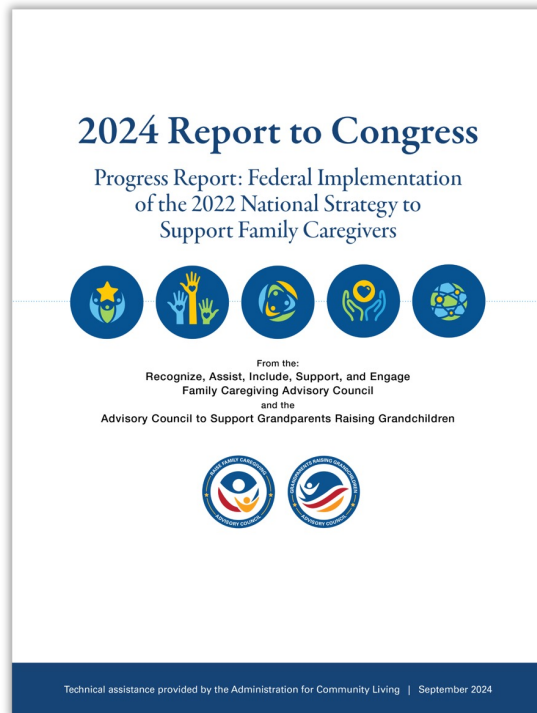
Opportunities to Advance Policy and Program

- Better communication between family caregivers, care receivers and service systems
- Include family caregivers early in the provision of care and planning
- Dedicate staff to engage with and include family caregivers
- Assess family caregiver needs along side those of the care receiver
- Partner with local community-based agencies to ensure caregiver needs are included in referrals for support

Opportunities to Advance Aging Policies & Programs

- Appoint family caregivers as board members to ensure their voices are included in all levels of policy planning.
- Policy-setting processes respond to family, kin and grandparent caregiver needs.
- Caregiver assessments to improve identification of caregivers who need services and supports.
- Ensure use of caregiver inclusive intake practices

Hot off the Press!!



2024 Federal Progress Report

[Report to Congress](#) – Reports on efforts to implement the National Strategy, including nearly 40 additional federal actions

[Data Tables](#) – Agency-by-agency updates on each of the 350 actions

[HHS Press Release](#) – Announcing the release of the report

New Federal Momentum to Support Family Caregivers

- April 2023 - Executive Order, [Increasing Access to High-Quality Care and Supporting Caregivers](#)
- [New Older Americans Act Regulations](#) – include the National Family Caregiver Support Program and the Native American Caregiver Support Program
- International collaboration and engagement
 - United Nations’ annual interactive debate on the rights of persons with disabilities
 - ACL provided input to the Canadian Centre for Caregiving Excellence (CCCE)
- Forty new federal actions since the Strategy’s release

Supporting Family Caregivers: Progress Toward Implementation of the 2022 National Strategy

October 9, 2024

LTQA Webinar



NATIONAL ACADEMY
FOR STATE HEALTH POLICY

nashp.org

Introductions

Wendy Fox-Grage

Senior Director
National Academy for State Health Policy
Email: WFGrage@nashp.org



About NASHP

The National Academy for State Health Policy (NASHP) is a nonpartisan organization committed to developing and advancing state health policy innovations and solutions.

NASHP provides a unique forum for the productive exchange of strategies across state government, including the executive and legislative branches.



RAISE Family Caregiver Implementation and Technical Assistance Center

HOME < AGING AND DISABILITIES < FAMILY CAREGIVING

TOPIC

Family Caregiving

The RAISE Act Family Caregiver Implementation and Technical Assistance Center



SHARE

Across the nation, state health programs depend on caregivers who provide critical support to help relatives, friends, and neighbors age in place while contributing about [\\$600 billion in unpaid health care services](#). To better support family caregivers, Congress passed the [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act](#) in 2018, which established the Family Caregiving Advisory Council tasked with creating the country's first national Family Caregiver Strategy. NASHP supports the council's

Funded by:
The John A. Hartford Foundation



nashp.org/family-caregiving

Featured Content



[Family Caregivers](#)



[The Family Caregiving Advisory Council and Faculty](#)



[Council Meeting Materials and Resources](#)



[State Resources](#)



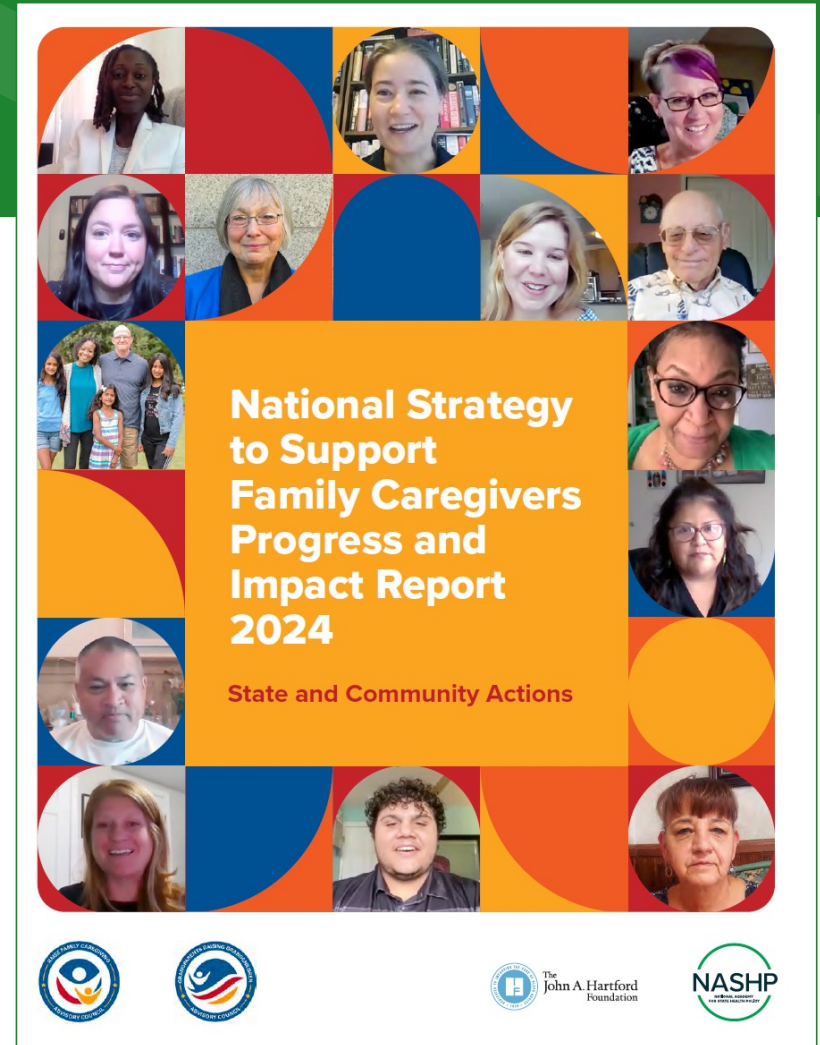
[Respite Care](#)

Hot Off the Press

- RAISE Progress and Impact Report in States and Communities
- State Caregiving Learning Collaborative
- SupportCaregiving.org Resource Guides

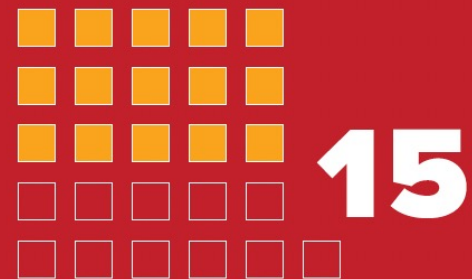
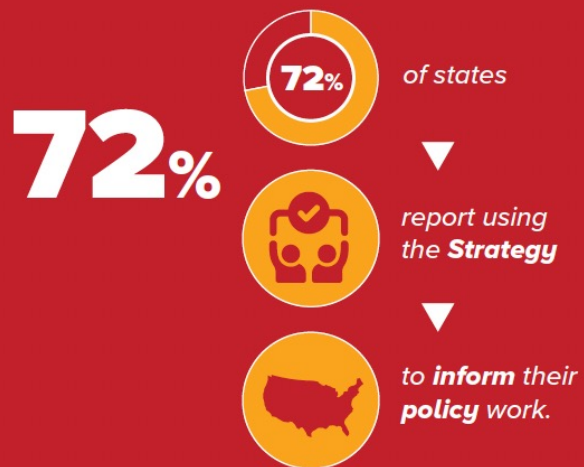
RAISE Impact Report

- Showcases early impacts of the 2022 National Strategy to Support Family Caregivers
 - Finds significant impact and national momentum
 - Demonstrates how the National Strategy affected local, state, federal, and organizational policy to support family caregivers
 - Highlights ways to keep the momentum growing



RAISE Impact Report: State Outcomes

Findings from the 2024 **AD**vancing States Survey on the National Strategy



15 of 26 states with multisector/strategic plans in place or in development report using **Strategy** recommendations in this work.



Arkansas has created an initiative to distribute quarterly \$300 Caregiver Respite Vouchers to caregivers for a total of \$1,200/year. Since November 2022, the state has given 350 vouchers to over 182 caregivers.



In **Delaware**, the Division of Services for Aging and Adults with Physical Disabilities launched the “Are you a caregiver campaign,” a marketing strategy to assist caregivers to self-identify as caregivers.



The **Montana** Department of Public Health and Human Services partnered with Montana State University to launch a Caregiver Respite Food Program to provide HelloFresh or Blue Apron meals to unpaid family caregivers. In the first 30 days of the program, over 420 adults and 74 children in 28 counties and Tribal communities participated in the program.

RAISE Impact Report:

State Lifespan Respite Care Grantees, who administer the Lifespan Respite Care Grant Program funded by the Administration for Community Living, are supporting the implementation of many respite actions outlined in the National Strategy.



The **North Dakota** Lifespan Respite program developed public service announcements for a Native Elder Caregiver Curriculum through Tribal radio stations (watch the first presentation in 2022, [Bring, Brag and Borrow](#)).



The **Virginia** Lifespan Respite Voucher Program will now provide up to \$595 in reimbursement to grandfamilies and kinship caregivers for the cost of child care or recreational camps so they can take time to rest and recharge.

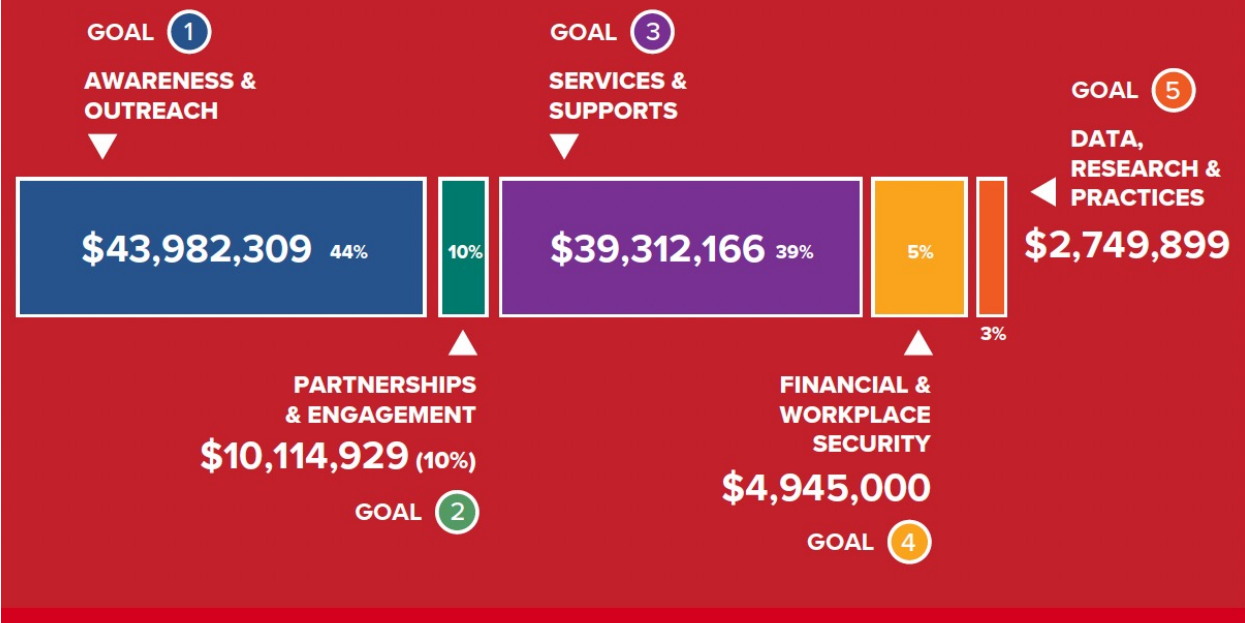


In **Wisconsin**, the WI Family and Caregiver Support Alliance introduced a Human Resources Care Kit to educate employers about family caregiver needs.

RAISE Impact Report:

State Lifespan Respite Care Grantees, who administer the Lifespan Respite Care Grant Program funded by the Administration for Community Living, are supporting the implementation of many respite actions outlined in the National Strategy.

Community Grants Awarded By Funders That Support RAISE Act Goals



RAISE Impact Report:

Family caregiving funders associated with Grantmakers In Aging awarded \$100 million (370 grants) in 2021 and 2022 to community organizations that directly align with one of the National Strategy's goals.

RAISE Impact Report: National Momentum for Caregiving



Eligible practitioners can now bill Medicare for providing training and education to caregivers of patients with chronic illnesses or disabilities thanks to new [billing codes](#) for caregiver training services.



USAging, the national association representing Area Agencies on Aging (AAAs), identified [the National Strategy](#) as one of its highest priorities for 2024.

According to a recent USAging survey of AAAs, **468** of 616 (76 percent) of [Area Agencies on Aging](#) have a caregiver program coordinator/manager on staff, and **67** (11 percent) would like to add one in the next three years; **209** (34 percent) have a caregiver trainer on staff, and **67** (11 percent) would like to add one in the next three years.

RAISE Impact Report: National Momentum for Caregiving



The ARCH National Respite Network dedicated its 2024 [conference](#) to elevating respite strategies in the National Strategy.



The [National Association of Counties \(NACo\)](#) held national meetings to promote innovative caregiving programs in counties.



[Grantmakers In Aging \(GIA\)](#) credits the National Strategy with providing a framework to better track how funders are supporting caregivers in their funding geographies.

RAISE Impact Report: Reflections on Impact



“The National Strategy gave MLTSS plans new ideas for how they could support family caregivers and how they could partner with others to do this work.”

Mary Kaschak, Long Term Quality Alliance and National MLTSS Plan Association



“RAISE was a signal moment. Prior to it, there had been no national approach to recognize and support family caregivers.”

Rani Snyder,
The John A. Hartford
Foundation

NASHP Caregiving State Policy Learning Collaborative

- NASHP invites states to apply for our 18-month Caregiving State Policy Learning Collaborative beginning January 2025 and ending June 2026
- Participating states will share best practices and opportunities to strengthen policies and strategies to improve family caregiver policy, building upon action steps in the National Strategy to Support Family Caregivers
- Supported by The John A. Hartford Foundation and the Ralph C. Wilson Jr. Foundation
- [Applications open now](#) and due **November 1!**

NASHP Annual Conference 2024



SupportCaregiving.org

What You Can Do

We all can work together to lighten the load for family caregivers. Explore the resource guides on this site for strategies that you can take to better support family caregivers.

Each guide provides concrete actions for a specific source of potential caregiver support – check back here as more are added!

Resources for:

[Family Caregivers >](#)

[Area Agencies on Aging >](#)

[Caregiving Youth >](#)

[Counties >](#)

[Employers >](#)

[Funders >](#)

[Kinship and Grandfamilies >](#)

[Managed Care Plans >](#)

Resources for State Officials:

[Respite Care >](#)

[Direct Care Workforce >](#)

[State Policy Strategies >](#)

[Person- and Family-Centered Practices >](#)

Resource Guide Examples



Family Caregiver Strategy Action Guide for MLTSS Plans

Executive Summary

The 2022 National Strategy to Support Family Caregivers — developed jointly by two U.S. advisory councils, with extensive input from the public — identifies policy recommendations for plans, states, and other partners to address caregivers' needs. The creation of this strategy was directed by the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act with the goal of supporting five aims:

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

Below, [Long-Term Quality Alliance \(LTQA\)](#), in partnership with the [National MLTSS Health Plan Association](#), highlights promising strategies for managed long-term services and supports (MLTSS) plans to support family caregivers.

Public Awareness and Outreach

More than **1 in 5** Americans has provided caregiving to an adult with functional limitations. This unpaid caregiving collectively contributes an estimated economic value of **\$600 billion per year**. Yet, given a lack of awareness about how caregiving is defined, few identify themselves as a caregiver. This lack of self-identification prevents caregivers from accessing caregiving supports and services that can increase the well-being of caregivers and, in turn, the well-being of the adults with functional limitations whom they serve. MLTSS plans can increase public awareness and education of the crucial role that family caregivers play in the larger health system to address this lack of caregiver identification and inclusion.



NATIONAL STRATEGY TO SUPPORT FAMILY CAREGIVERS

Action Guide for Counties

January 2024

Supporting Caregivers in the Workplace



Addressing caregiving responsibilities while in the workplace will likely affect most — if not all — workers at some point. It is estimated there are **53 million people** providing informal, often unpaid care to loved ones in the United States. Without proper support, these workers must juggle significant familial and professional responsibilities that can either hinder their ability to work or completely remove them from the workforce. The loss of income connected to family caregiving amounts to an estimated **\$522 billion each year**.

Employers that wish to help their workers with caregiving responsibilities may not know where to begin. The [National Strategy to Support Family Caregivers](#) — developed jointly by two U.S. advisory councils, with extensive input from the public — includes nearly 500 actions that can be adopted at every level of government and across the public and private sectors. As HR professionals, [SHRM](#) members drive positive workplace policies that create better workplaces and better worlds. Organizations need to assess their ability and capacity to offer support for their workers.

As a starting point, SHRM recommends HR practitioners take the following three steps:

1. **Design benefits that reflect the needs of your workers with caregiving responsibilities.** While every employer is not able to offer the same benefits, offering benefits that would appeal to workers with caregiving responsibilities is a way to attract and retain top talent while enabling the worker to remain in the workplace. Shaping benefits to accommodate these workers will signal the organization's support of caregivers. While differences in organizational size, industry and profit-level will affect the level of benefits, below are some suggestions to consider:
 - a. **Flexible work arrangements** such as allowing family caregivers to use flexible work hours, compressed work weeks, paid leave programs that allow for "life events," telework or structuring job descriptions around tasks that can be completed remotely at flexible times of day.
 - b. **Financial wellness benefits** — including access to emergency funds, financial planning, and tuition and student loan assistance — offer an important promise of financial health and security. They can also be welcome incentives when choosing a new workplace, as caregivers often face financial costs associated with the direct cost of care, loss of income due to missed work and diminished earning capacity due to prolonged absences from the workforce.
 - c. **Additional benefits** such as dependent care flexible spending accounts; health care offerings that allow for telemedicine; subsidized or unsubsidized childcare centers or programs; eldercare centers or programs; employee assistance programs (EAPs) and other referral services; and emergency child/eldercare benefits.

Contact us at governanceaffairs@shrm.org

SupportCaregiving.org Partners



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Questions?



Thank You!

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