

The RAISE Act and the National Strategy to Support Family Caregivers

A Presentation for The Long Term Care Discussion Group

October 12, 2022


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The Recognize, Assist, Include, Support & Engage (RAISE) Family Caregivers Act - Overview

- Became law: Jan 22, 2018
 - Three key components:
 - Family Caregiving Advisory Council
 - Exempt from FACA requirements
 - 15 non-federal members
 - ACL, VA, CMS plus cross-federal agency representation (HHS, CNS, Ed, CFPB)
 - First convened in August 2019
 - Three virtual, public meetings per year
 - Current council appointments end in September 2022
 - Initial Report to Congress (annual updates – TBD)
 - National Strategy to Support Family Caregivers (biennial updates)
 - Annual appropriations - \$400K
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The Initial Report to Congress



- Delivered to Congress on 9/22/21
- Disseminated publicly on 9/23/21
- Caregiver “stories”

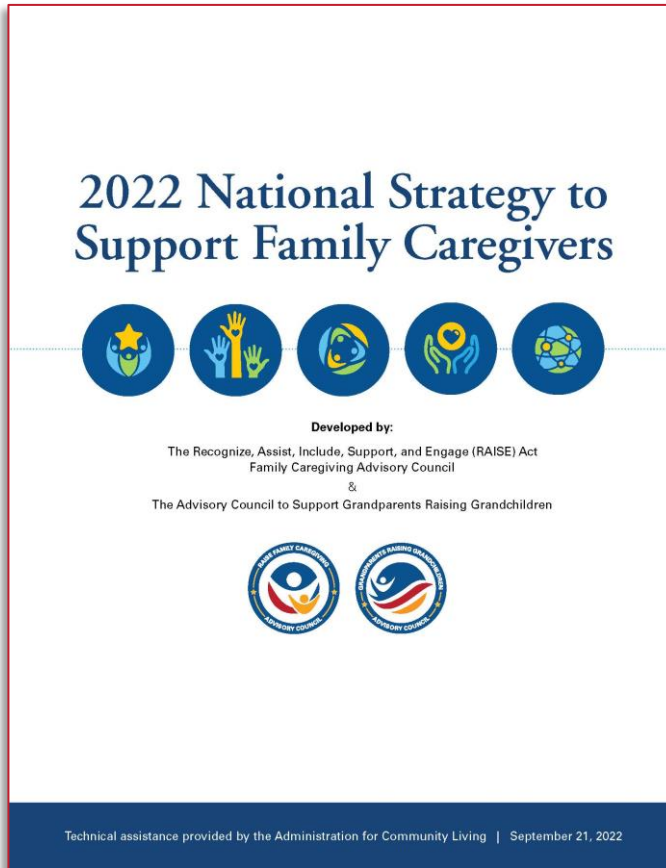
National Strategy to Support Family Caregivers

Grounded in 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

* RAISE and Grandparent Advisory Councils

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.

First Principles: Cross-Cutting Considerations for Family Caregiver Support

- Placing the family and person at the center of all interactions
- Addressing trauma and its impacts on families
- Advancing equity, accessibility, and inclusion for family caregivers in underserved communities
- Elevating direct care workers as family caregiving partners

Casting a Wide Net

Public Engagement

- 2019: Two Requests for Information (RFI)
- 2020: 13 Focus Groups/80 participants
- 2020: Stakeholder listening sessions
- 2021: 17 Key informant interviews and 22 listening sessions with 145 stakeholder organizations:
 - State and local entities
 - Employers of all sizes and unions
 - Health and LTSS providers
 - Respite and community-based organizations
 - Faith-based
 - Philanthropies

Administration & Agency Engagement

- Federal agency membership on the council
- HHS Secretary participation in council meetings
- More than 350 commitments from federal agencies
- White House Domestic Policy Council briefings and meeting participation

Resources for Implementation


Funded by: The John A. Hartford Foundation
National Academy for State Health Policy (NASHP)

- National Alliance for Caregiving
- UMass Boston
- Community Catalyst

[The RAISE Family Caregiver Resource and Dissemination Center](#)



Looking Ahead

- Upon Release of the Strategy
 - Stakeholder engagement
 - Social media, print and electronic media
 - National Strategy [Public Comment Period](#) – October 1 – November 30, 2022
 - NASHP and partners will:
 - Analyze federal actions to identify opportunities for collaboration and coordination of activities
 - Analyze public comments for use by next councils to update reports and the Strategy
 - 2022 National Family Caregivers Month observation (November)
 - Presidential Proclamation
 - Social media and stakeholder engagement
 - Planning for new council appointments
- 

Thank you

Building a National Strategy: Obtaining Public Input

Long Term Care Discussion Group
October 12, 2022

Acknowledgements:

- Our funders: The John A Hartford Foundation, with a subcontract from NASHP, in collaboration with ACL
 - Greg Link (ACL) and Scott Bane and Rani Snyder (The John A.Hartford Foundation)
- The research team:
 - Eileen Tell, ET Consultants
 - Pamela Nadash and Marc Cohen , LeadingAge Center@UMass Boston
 - Carol Regan and Siena Ruggeri, Community Catalyst
 - Graduate research assistants from the Gerontology Department at UMass Boston: Taylor Jansen, Andrew Alberth, Lilian Tran, and Shan Qu
 - Our project officer, Wendy Fox-Grage of NASHP



Research Objectives

- Support the Advisory Council in its decision-making
- Phase I: Provide feedback on caregiver policy priorities
 - Council developed five goals with supporting recommendations
 - Submitted its mandated Report to Congress
- Phase II: Help inform a roadmap for the National Strategy, focusing on priority topics that emerged from the Phase I consumer listening sessions
 - Council developed its proposed National Strategy
- Phase III: Analyze feedback on the National Strategy
 - Used to focus the Council's ongoing work in rolling out the National Strategy

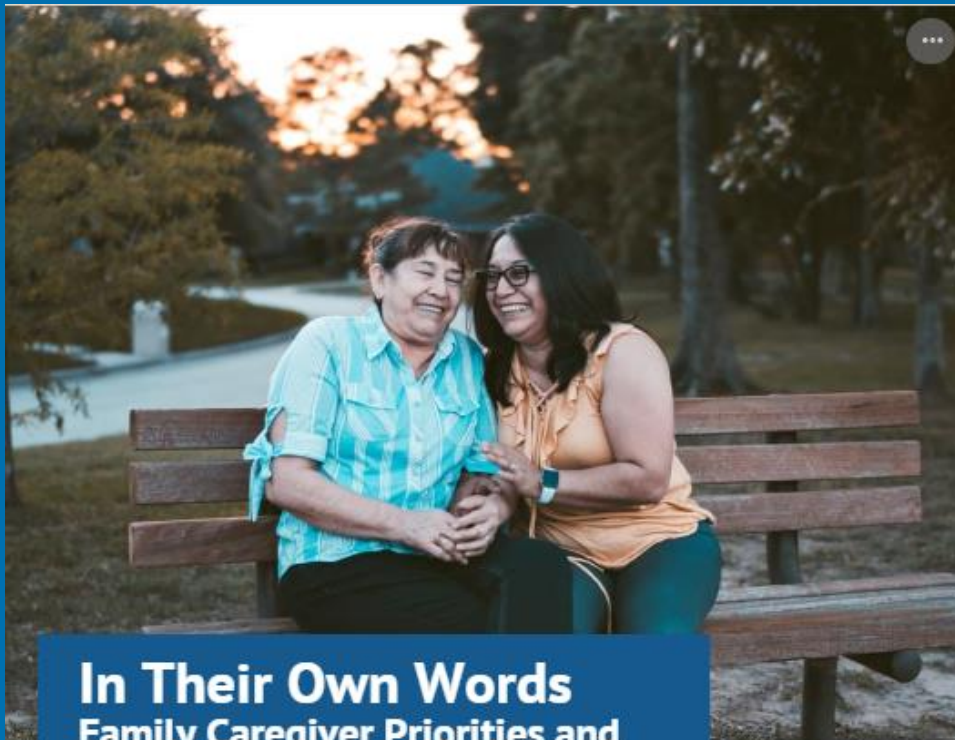
Research Activities

- Phase I – issue identification
 - RFI Analysis – 1613 responses/ 1,147 from family caregivers
 - Caregiver Focus Groups – 12 groups
 - Stakeholder Listening Sessions – 6 sessions
- Phase II -- strategies
 - Key informant interviews -- 17
 - Focus groups – 16 groups

Phase I RFI Analysis

Table 1: RFI Respondents, by Category		
Respondent group	N	%
Advocacy	184	11%
Community-Based Organization	154	10%
Government	31	2%
Caregivers*	1203	75%
Other Research	15	1%
University	26	2%
Total	1613	

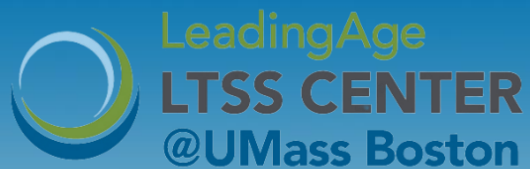
**997 cases self-identified as individual caregivers. A further 206 were coded as such based on blank entries in the "organization" field.*



In Their Own Words Family Caregiver Priorities and Recommendations: Results from a Request for Information

Pamela Nadash, PhD
Taylor Jansen, MS
Eileen J. Tell, MPH
Marc Cohen, PhD

February 16, 2021



Research bridging policy and practice



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www.communitycatalyst.org



Download from:
<https://www.nashp.org/in-their-own-words-family-caregivers-from-across-the-country-share-their-priorities-and-recommendations/#top>



Phase I Caregiver Focus Groups

- 9 groups designed to be representative
 - Used research firm to recruit / ensured access to technology
 - Focus varied
 - 4 covered all topics
 - 3 focused on caregiver services and supports
 - 2 exclusively on financial and workplace issues
 - Populations varied
 - Parents of children with support needs (both minor and adult)
 - Those supporting adults with support needs
- 1 group conducted in Spanish with Spanish-speaking (only) and Spanish-English speaking caregivers
- 1 group of teen caregivers
- 1 group of **kinship/grandparent caregivers**

Overall Findings: RFI and Focus Groups

- Findings on priority concerns:
 - Financial considerations
 - Direct pay for caregiving
 - Workplace accommodations
 - Tax policy and other solutions
 - Caregiver training and education
 - Respite care
 - Information and referral
 - Care coordination and care transitions
- And cross-cutting themes awareness, inclusion, and need for evidence

Phase I Stakeholder Sessions

- Six sessions organized by RAISE goal (two for goal 3)
- 42 organizations participated in six two-hour sessions (60 groups were invited)
- Objectives:
 - Engage key organizations in the work of the Council
 - Start to generate ideas about specific action steps related to recommendations that support the Council's five major goals
 - Promote continued participation and involvement as the Council develops its national strategy
 - Identify key leaders for the national advocacy work ahead

Phase I Stakeholder Sessions: Key Themes

Needs for:

- Conducting a major awareness and education campaign about caregiving
- Expanding HCBS and eliminating waiting lists
- Involving a range of stakeholders, including CBOs, healthcare professionals, and employers
- Respecting the broad range of cultures and experiences among caregivers
- Involving caregivers in all aspects of program and policy change
- Broadening technology and broadband access
- Providing systematic access to training and other supports for caregivers
- Improving the wages, benefits, and training of the paid caregiving workforce

Recognize, Assist, Include, Support, & Engage (RAISE)
Family Caregivers Act
Initial Report to Congress

Prepared by: RAISE Family Caregiving Advisory Council

With assistance from: Administration for Community Living,
an operating division of the U.S. Department of Health and Human Services



September 22, 2021

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

Phase II: Building Out Strategies

- **Stakeholder Listening Sessions**

- Organized to represent key stakeholder groups
- Obtain shared and divergent perspectives on how to address specific goals and recommendations
- Identify specific solutions, timeframes, implementation challenges and other components of proposed strategies
- Convened 16 Listening Sessions, each 90 minutes, over Zoom
- Invited 253 individuals/stakeholder organizations*
- Overall, heard from 103 unique stakeholder organizations

Phase II Participants

POPULATION/TOPIC	KEY INFORMANT INTERVIEWS	LISTENING SESSIONS
EMPLOYERS: Intermediaries, academics, HR reps, and public policy perspectives	5	3
RESPITE CARE	3	1
LTSS PROVIDERS/DIRECT CARE WORKFORCE	2	2
HEALTH PROVIDER	3	1
COUNTIES	1	1
COMMUNITY-BASED ORGANIZATIONS (CBOs) and FAITH-BASED ORGANIZATIONS (FBOs)	3	
GEOGRAPHICALLY-BASED LISTENING SESSIONS: Rural/Urban/Suburban CBOs		2
POPULATION-SPECIFIC LISTENING SESSIONS: Aging, Disability, Indigenous communities, People of Color, and Faith-Based Organization		5
Total	17	16

2022 National Strategy to Support Family Caregivers



Developed by:

The Recognize, Assist, Include, Support, and Engage (RAISE) Act
Family Caregiving Advisory Council

&

The Advisory Council to Support Grandparents Raising Grandchildren



Download from:
<https://acl.gov/CaregiverStrategy>

Phase III: Analyzing Feedback on the Proposed National Strategy

National Strategy – Please Weigh In!

- The 2022 National Strategy to Support Family Caregivers was released 9/21/22.
- It contains more than 350 actions federal agencies can take
- It also outlines actions for state and local governments, philanthropies, employers, and community-based, faith-based, and nonprofit organizations
- Please submit your thoughts and comments at <https://acl.gov/CaregiverStrategy/Comments>



I NEED HELP WITH



Provide feedback on the National Strategy to Support Family Caregivers.

Thank you for taking the time to review and provide comments on the 2022 National Strategy to Support Family Caregivers.

Your responses to the questions below will help the Advisory Councils identify priorities for future updates of the Strategy. Please do not include personally identifiable information in your responses as some public comments may be published in future documents released by the RAISE Family Caregivers Act Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren.

Instructions: Please select one component of the Strategy from the drop-down menu below and provide comments on that document. If you could like to provide general comments that apply to the Strategy as a whole, please select "Global Comment for all Four Components." When you have finished providing your comments, click "submit." If you would like to comment on another component of the Strategy, please fill out this form again. There is no limit to the number of forms you can submit.

First

Last

Email

Please let us know how you are involved in caregiving. Which of the following best describes your role? (Select all that apply.)*

- A family caregiver
- Employed by an organization that serves family caregivers
- Employed by a government program that serves family caregivers
- An advocate for family caregivers
- A researcher on caregiving topics
- Other/Prefer not to say

Which component of the strategy are you addressing with your comment?*

Which component of the strategy are you addressing with your comment?*

- Select -



Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?*

1500 character(s) remaining

Are there issues that are not covered in this component that should be addressed in future updates? *

1500 character(s) remaining

If you have additional comments on any aspect of the Strategy, please provide them below.

500 character(s) remaining

The RAISE Act Family Caregiver Resource and Dissemination Center

October 12, 2022



NATIONAL ACADEMY
FOR STATE HEALTH POLICY



The
John A. Hartford
Foundation



RRF

Foundation
for Aging

nashp.org

Speaker

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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.

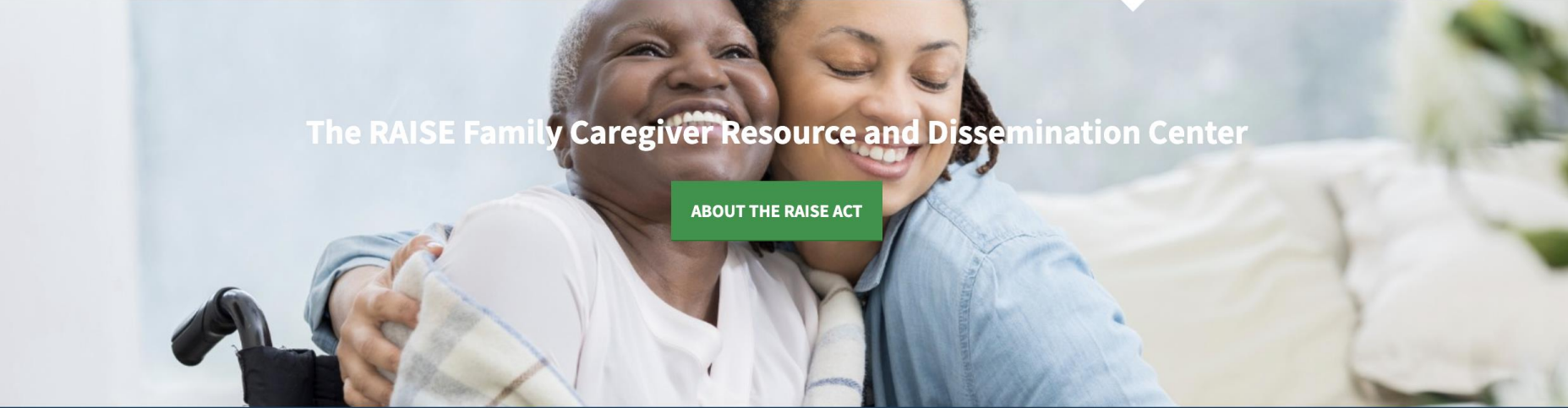
NASHP provides a unique forum for the productive exchange of strategies across state government, including the executive and legislative branches.



The RAISE Family Caregiver Resource and Dissemination Center



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[ABOUT THE RAISE ACT](#)

- THE FAMILY CAREGIVING ADVISORY COUNCIL AND FACULTY
- COUNCIL MEETING MATERIALS AND RESOURCES
- STATE RESOURCES
- RESPITE CARE

NASHP's Role

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; and
4. Facilitate uptake and implementation of Council recommendations at the state level.

The RAISE Family Caregiver Resource and Dissemination Center

- Blogs, briefs, and webinars
- Council meeting materials
- State Policy Roadmap for Family Caregivers
- State institute on family caregiving policy

The RAISE Family Caregiver Resource and Dissemination Center

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THE FAMILY CAREGIVING ADVISORY COUNCIL AND FACULTY

COUNCIL MEETING MATERIALS AND RESOURCES

STATE RESOURCES

RESPITE CARE

ACL Administration for Community Living

NASHP National Association of State Home Care Administrators

The John A. Hartford Foundation

RRF Foundation for Aging

Council Meeting Materials and Resources

Respite Care

Support to RAISE Act Council

- Report to Congress: Published in September 2021 with input from NASHP's *Medicaid Supports for Family Caregivers* report
- Subcontracted with National Alliance for Caregiving to produce *Faces of Caregiving*
- Contracted with UMass Boston and Community Catalyst to analyze 1,600 responses to RFI and publish a report on the findings

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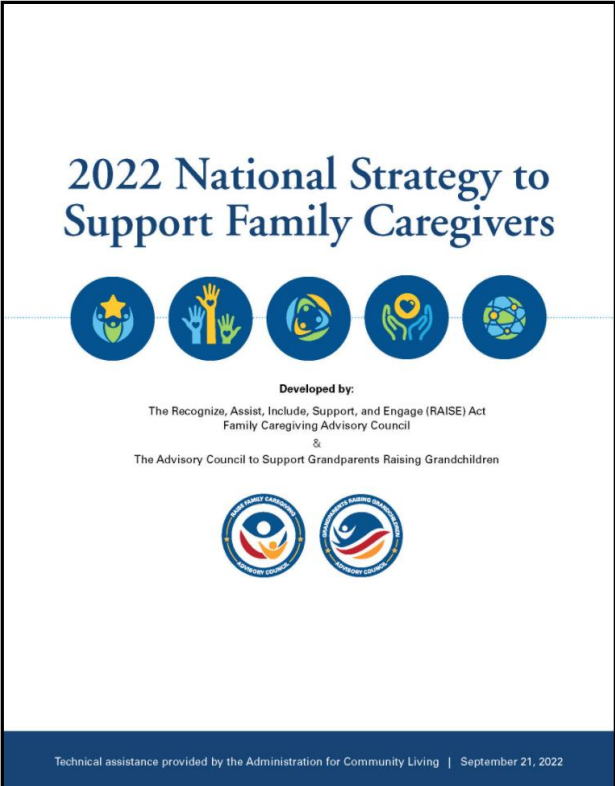
 
Administration for Community Living

    
RECOGNIZE **ASSIST** **INCLUDE** **SUPPORT** **ENGAGE**

September 22, 2021

35

The National Strategy



RAISE Act State Policy Roadmap for Family Caregivers

- Six papers highlighting state strategies and promising practices



Public
Awareness
and
Outreach



The Direct
Care
Workforce



Financial
and
Workplace
Security

RAISE Act State Policy Roadmap for Family Caregivers

- The Roadmap supports states in developing supports for family caregivers of older adults by identifying innovative and emerging policy strategies



Family
Caregiver
Services
and
Supports



Using
Research,
Data, and
Evidence-
Informed
Practices
to Support
Family
Caregivers



Engagement
of Family
Caregivers
in Health
Care
Systems

RAISE Act State Policy Roadmap for Family Caregivers

- **Public Awareness and Outreach**

- Strategies:

- Launching public outreach campaigns
- Specifying support targeted to family caregivers in regulation, manuals, and other documents
- Building state plans on aging that include family caregiver supports
- Creating and engaging state family caregiving taskforces and councils

RAISE Act State Policy Roadmap for Family Caregivers

- **Public Awareness and Outreach**
- State examples of a range of approaches:
 - Minnesota
 - Washington State
 - New York State

RAISE Act State Policy Roadmap for Family Caregivers

- **Engaging Family Caregivers in Healthcare Services and Systems**
- Strategies:
 - Foster caregivers' inclusion on the care team
 - Help family caregivers function effectively as a member of the care team
 - Build identification & assessment into state funded programs and services
 - Ensure family members receive the information they need to care for the individual in the new setting prior to transitions in care setting, especially hospital discharge
 - Ensure providers and other members of the care team know how to effectively engage family caregivers
 - Measure family caregiver engagement and incorporate the information into quality improvement and value-based payment efforts

RAISE Act State Policy Roadmap for Family Caregivers

- **Engaging Family Caregivers in Healthcare Services and Systems**
- State examples of a range of approaches:
 - Georgia
 - Tennessee
 - Illinois

RAISE Act State Policy Roadmap for Family Caregivers



Supporting Family Caregivers: A Roadmap for States

The 2022 National Strategy to Support Family Caregivers provides a roadmap for states to better support family caregivers. This overview highlights policy strategies and promising practices for states.



The Challenge

The pandemic heightened reliance on family caregivers and the shortage of direct care workers who provide care. States are being called upon to address these crises.

A Historic Solution

The National Strategy to Support Family Caregivers, as required by the RAISE Act, was presented to the U.S. Congress in September 2022. The strategy lays out actions — by federal and state governments, communities, employers, and others — to increase recognition and support for family caregivers.

State Roadmap

To inform the National Strategy, the National Academy for State Health Policy (NASHP) created the RAISE Act State Policy Roadmap for Family Caregivers. The roadmap helps states interested in expanding supports for family caregivers by offering the following policy strategies and promising practices.



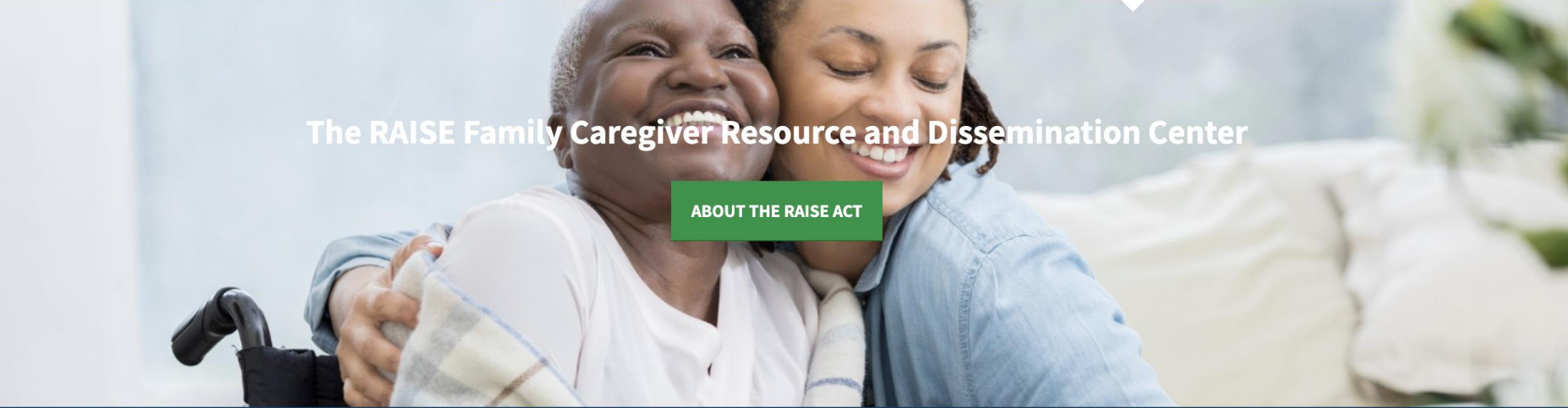
National Strategy Dissemination: Asks

- Help disseminate the National Strategy (social media promo, press release, direct emails, e-news)
- Provide feedback during public comment period (10/1 through 11/30)
- Analyze the National Strategy for action steps that your agencies/organizations can take
- November Twitter chat, National Family Caregivers Month

raisefamilycaregiving.org



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Q&A



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