

Lifespan Respite Learning Collaborative

*Implementing Respite Actions in the National
Strategy to Support Family Caregivers*



Learning Collaborative Launch
February 16, 2023

Agenda

WELCOME AND INTRODUCTIONS

PURPOSE OF THE LEARNING COLLABORATIVE	Jill Kagan, Director, ARCH National Respite Network and Resource Center
PRESENTATION	<i>Respite Implementation: National Strategy to Support Family Caregivers</i>
	Wendy Fox-Grage Senior Policy Fellow National Academy for State Health Policy
Q&A	
DISCUSSION ON NEXT STEPS	<i>Learning Collaborative Organization Structure and Content</i>
	Megan Kluth, ARCH Consultant and Learning Collaborative Facilitator
THANK YOU AND WRAP UP	Lori Stalbaum, Administration for Community Living Jill Kagan, ARCH

Purpose of Learning Collaborative

- ❑ Build familiarity with the 2022 National Strategy to Support Family Caregivers
- ❑ Identify respite strategies that your state is already doing or could begin, and help develop action plans for implementation
- ❑ Provide peer support, peer learning, expert guidance and technical assistance
- ❑ *Policy to Practice Brief: The Role of Respite in the National Strategy to Support Family Caregivers*

archrespite.org/images/Learning_Collaborative/Policy_to_Practice_Brief.pdf

Respite Implementation: National Strategy to Support Family Caregivers

Lifespan Respite Grantee and Partner Learning Collaborative

February 16th, 2023



NATIONAL ACADEMY
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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.



RAISE Family Caregiver Resource and Dissemination Center

<https://www.nashp.org/the-raise-family-caregiver-resource-and-dissemination-center/>

[HOME](#) < [AGING AND DISABILITIES](#) < [FAMILY CAREGIVING](#)

TOPIC

Family Caregiving

The RAISE Act Family Caregiver Resource and Dissemination 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 [\\$470 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 work by providing resources, convening experts, and supporting states as they develop policies.

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Featured Content



[Roadmap for Family Caregivers](#)



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



[Council Meeting Materials and Resources](#)



[State Resources](#)



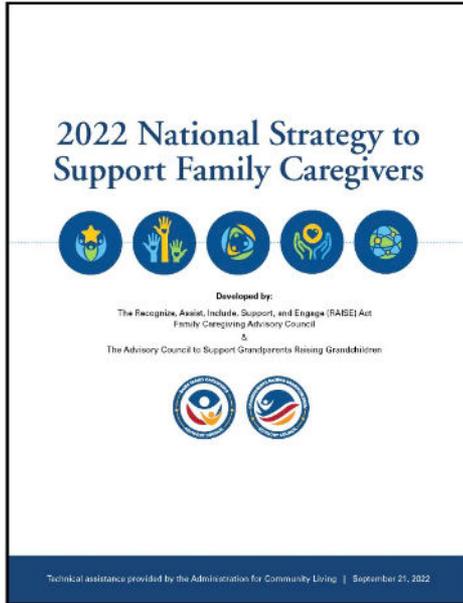
[Respite Care](#)



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2022 National Strategy to Support Family Caregivers

acl.gov/CaregiverStrategy



- The Strategy includes about 350 federal actions and 150 state, community, and private partner actions to achieve the goals
- Five goals provide the framework for the Strategy
 - Goal 1: Increase awareness of and outreach
 - Goal 2: Advance partnership and engagement
 - Goal 3: Strengthen services and supports
 - Goal 4: Ensure financial and workplace security
 - Goal 5: Expand data, research, and evidence-based practices

Implementing Respite Actions: RAISE Act State Policy Roadmap

<https://nashp.org/supporting-family-caregivers-a-roadmap-for-states/>

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.

Public Awareness and Outreach

To increase outreach and identification of family caregivers, who often do not self-identify as caregivers or know where to turn for information, states can...

- Launch public outreach campaigns for family caregivers
- Specify outreach targeted to family caregivers in regulation, policy, procedure manuals, and state plans on aging
- Create and engage state family caregiving taskforces, councils, and commissions



Get the Roadmap.
[Explore more recommendations, strategies, and state actions](#) to build public awareness and reach out to caregivers

State Examples

From 2014 through 2019, 12 states created family caregiving task forces. Explore the map to learn more.



INTERACTIVE MAP

Respite Action Guide/Explainer on Respite Care

- NASHP/ARCH collaboration with feedback from this Learning Collaborative
- Outlines these respite actions within the National Strategy and how states can implement

Respite Actions within National Strategy:

Goal 1 - Increase awareness of and outreach to family caregivers

- To provide **up-to-date information** about local respite options
- To develop **culturally appropriate toolkits and resource guides** that can be used by local communities
 - Ex: The value of caregiver assessments and respite care
- To seek out innovative ways to **conduct outreach and data collection efforts** that are specific to their sector

Respite Actions within National Strategy:

Goal 3 - Strengthen services and supports for family caregivers

- To increase access to **safe and reliable drop-in respite** care programs **during emergencies or unanticipated events**
- To **increase the availability** of a range of options for both in-home and out-of-home respite services:
 - **Vouchers**
 - **Self-directed programs**
 - **Culturally specific programs**
 - **Explore alternate respite models** allowed under the Lifespan Respite Care Program and the National Family Caregiver Support Program: **volunteer and fee-for-service models, mobile adult day care models for rural communities**
- To develop and disseminate **training resources** to expand the capacity of respite care programs to meet the needs of family caregivers of **individuals with medically complex care needs**.
- To create a **'What respite means to me' tool** and add this resource to existing resource lists and websites.

Respite Actions within National Strategy:

Goal 3 - Strengthen services and supports for family caregivers (continued)

- To examine **peer respite models and develop programs that leverage best practices**, including:
 - **Promote federally funded resources** to community members, including the National Respite Locator, the Eldercare Locator, the Disability Information and Access Line (DIAL), and the National Alzheimer's Call Center
 - Tap into **church-based volunteer networks**
 - Establish **cooperative respite models** that allow caregivers to “purchase” support for their family member with volunteer hours.
 - **Provide adult day services** in a supervised group setting within the community.
- To **use the widest possible definition of respite**, meaning it can include any activity that provides the caregiver with a meaningful break.

Respite Actions within National Strategy:

Goal 5 – Expand data, research, and evidence-based practices to support family caregivers

- Expand evidence-based research on respite that can be disseminated to the appropriate populations or groups.

State Examples - Lifespan Respite Care Program Grantees

- The [NY Connects Resource Directory](#) provides statewide information and assistance to individuals across age and disability types, their caregivers, and professionals.
- Grant program to test a new respite training curriculum for respite providers. New York is currently piloting an [online respite worker training](#) that embeds ARCH's Respite Care Professional Core Competencies that will result in respite training certification and the development of a respite provider directory.
- Six mini grants were awarded to organizations across the state to train volunteer respite workers using an in-person training curriculum.

New York: Expanding respite workforce and service access



State Examples - Lifespan Respite Care Program Grantees

- In 2018, State Committee on Respite published [An Update on Sustaining South Carolina's Family Caregivers through Respite](#). The leadership and state plan have helped with the coordination of respite funds from several programs—the State Voucher Program, Alzheimer's Disease, Family Caregiver Support, and Lifespan Voucher Programs—to ensure access to families across the lifespan.
- Utilized grant funds for educational purposes, including the development of respite informational videos, infographics, and a physician-directed caregiver identification/assessment tool.
- Mini-grants to six churches developed “break rooms” for respite for family caregivers in their congregations/communities.

South Carolina: *Coordinating respite care funding*



Next Steps

- Call to Action: Read and speak up about the National Strategy at acl.gov/CaregiverStrategy
- New RAISE Advisory Council to be announced in Spring, will focus on an update and implementation
- Public comments are being analyzed
- Full Council meetings are live-streamed and open to the public at acl.gov/raise
- The plan: to update the National Strategy every two years

Thank you!



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Moving Forward through the Learning Collaborative

Meghan Kluth
Learning Collaborative Facilitator

Proposed Collaborative Structure and Activities

- ❑ Facilitate peer learning opportunities to learn about other states' approaches, bright spots, and lessons learned.
- ❑ Encourage mentorships/collaborations between state grantee and coalition leaders outside the Collaborative.
- ❑ Bring in outside speakers to help provide resources for group.
- ❑ Assist NASHP in the development of a Respite Action Guide.
- ❑ Document learnings and challenges to help inform next steps for the new RAISE Family Caregiving Advisory Council (to be appointed in 2023).

Discussion

What are your reactions to these activities?

Are there any you want to adjust or add?

Do you have any suggestions for preferred peer learning strategies?
Breakout groups by topic? Meeting outside the collaborative? Others?

Meeting Structure

- ❑ We will meet monthly via Zoom throughout 2023.
- ❑ The next meeting will be **March 16th**. Beginning in April, propose meeting on the 1st Thursday from 2:00-3:30 pm EST.
- ❑ ***Polling Question:*** Do these meeting times work for you?
- ❑ Meetings will be recorded but we request that you participate in all meetings if possible.
- ❑ We will use the meeting time for group discussion as well as presentations.

Ideas for Future Meeting Topics

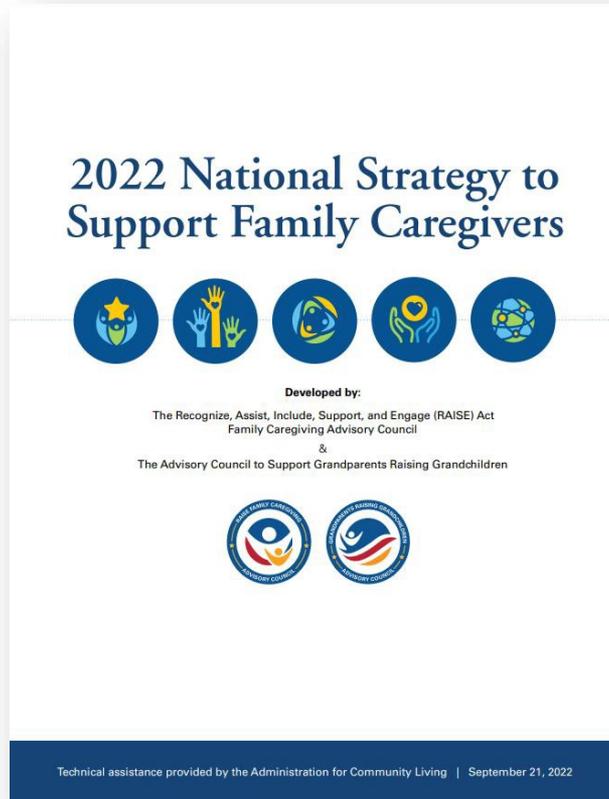
- ❑ Jamboard link -
<https://jamboard.google.com/d/1Nxv80qCPydX4IWsaQQP3-r4vN65Wlp3INylg9swdZSo/edit?usp=sharing>
- ❑ These boards will be available between meetings for you to add ideas.
- ❑ To add an idea, click the square sticky note icon on the left and begin typing.

For Next Meeting

➤ Review all components of the 2022 National Strategy to Support Family Caregivers, especially #4 on State Actions:

1. National Strategy
2. First Principles: Cross-Cutting Considerations for Family Caregiver Support
3. Federal Actions
4. Actions for States, Communities and Others

All four documents can be found at <https://acl.gov/CaregiverStrategy>.



Next Steps

Watch your inbox for upcoming meeting invites.



Determine which grantee team members and partners from your state will attend regularly.



In March, we will discuss alignment between National Strategy and current activities your state is already working on.

For More Information



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Wrap up and Closing Remarks
