

# “RAISEing” The Respite Bar: The National Strategy as a Framework for Leadership

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“How do we create a world where caregiving is central to who we are, as opposed to something that diverts us or is a sideline of our real lives?”

–Carol Zernial, RAISE Council Co-Chair

LET'S TALK ABOUT LEADERSHIP

# lead·er·ship

/'lēdər,SHɪp/

*Noun*

The ability of an individual or a group of people to influence and guide followers or members of an organization, society or team

# lead·er·ship

/'lēdər,SHɪp/

*Noun*

The *art* of motivating a group of people to act towards a common goal

# Building Blocks of Leadership

- Mobilization towards a vision
- Establishing a common purpose.
- Fostering participation
- Consensus building
- Resource marshalling
- Providing guidance, direction, and motivation
- Expecting excellence
- Persistency and consistency

# THE NATIONAL STRATEGY TO SUPPORT FAMILY CAREGIVERS: THE NUTS AND BOLTS

“I would like to offer for any ‘decision maker’ to spend a day with me and my family and see what it truly takes to care for someone with significant impact of a disability. I think only then can we move forward with an actual picture of what we ... are up against.”

-Respondent, 2019 ACL RFI



# Public Engagement at Every Step

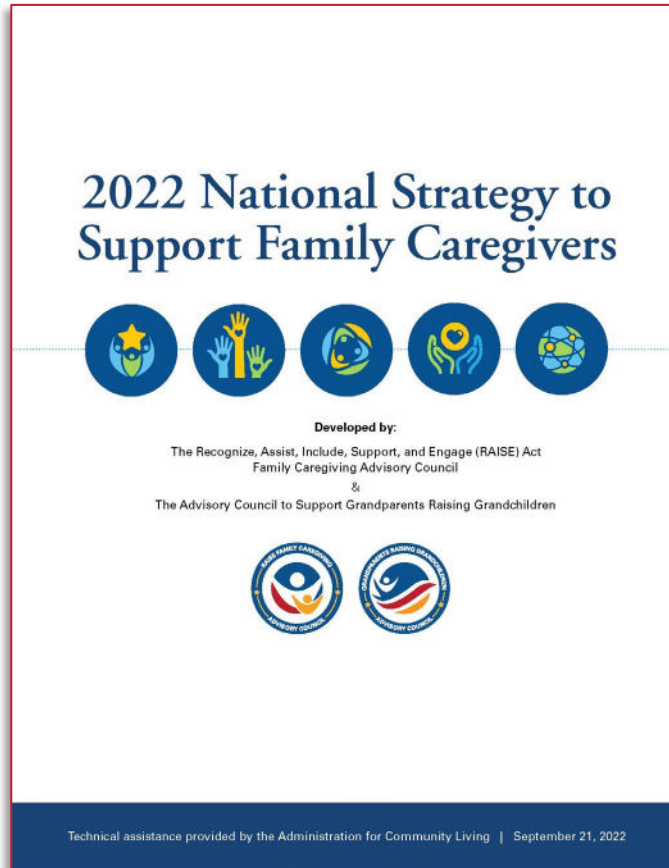
## **For Starters:**

- ACL RFI (2019)
  - 1613 responses
  - 75% from caregivers
- Caregiver Focus Groups
  - 13 sessions/80 individuals
  - All populations, including teens
  - Delved into RFI findings
- Stakeholder Listening Sessions
  - Aging and disability organizations
  - 60 invited/42 participated
  - 6 sessions focused on operationalizing the recommendations
- Public input during council meetings

## **From 12/2020 - 12/2021:**

- Interviews & Listening Sessions
  - 17 key informant interviews
  - 22 listening sessions
  - 145 stakeholder organizations
- Stakeholders included
  - State entities
  - Counties
  - Employers (large and small)
  - LTSS and healthcare providers
  - Respite providers
  - CBOs/faith-based organizations

# 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.

# 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

# What the Strategy is...and is Not

## The Strategy is...


- A vision and roadmap for change
- A baseline for action and progress
- A framework for all caregiving situations and experiences
- Intended for use by many stakeholder groups

## The Strategy is not...

- A timeline or how-to document
- A list of requirements or “musts”
- Specific to any particular caregiving situation, topic or condition
- Exhaustive of all the possibilities

**Most Importantly...**It's the first...Not the last

# A “Whole of Society” Approach is Needed

- States, tribes, county governments, and communities
  - Community-based providers of long-term services and supports
  - Child welfare agencies
  - Kinship support systems
  - 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!
- 

# Public Response and Comments

## 10/1/22 – 12/31/22

- Nearly 600 unique respondents/1000+ responses
  - Majority of comment focused on Goal 3, followed by Goal 4
  - Raising awareness of family caregiving and its associated issues was also prominent
- Top priorities for future iterations of the Strategy to address:
  - Affordability, supply and quality of direct care work force
  - General need for additional services and supports
  - Caregiver training and education
- More specific actions for accountability by federal agencies
- More focus on the important role of states in implementing the Strategy
- [Analysis of Public Comments Report](#)

# A Catalyst for Change

- Approximately 40 additional Federal actions added
- The President's Care Executive Order
- ACL's new National Caregiver Support Collaborative
- Updated Older Americans Act Regulations
- CMS' new Guiding and Improved Dementia Experience (GUIDE) Model
- International attention and focus

# THE NATIONAL STRATEGY AS A FRAMEWORK FOR LEADERSHIP IN RESPITE



“...I think even we’re still struggling when just developing the awareness of respite care services and making sure that not only providers, but caregivers are aware of it.”

-2021 Caregiver Listening Session

## How Can You RAISE the Respite Bar?

- What can you do/have you done to raise awareness about respite?
- What can you do/are you doing to address the direct care workforce crisis?
- Respite Coalitions: Is there room for you taking on greater leadership roles in coordination, across systems and programs?
- How are you connecting with managed care programs to encourage them to cover respite?

# How Can You RAISE the Respite Bar?

- How are you currently defining respite? Could your definition be broader?
- Are you maximizing your partnerships and collaborative opportunities with communities of faith?
- What is the latest effort out there to empower family caregivers to seek support?

SUPPORTING YOUR WORK...LOOKING AHEAD

“We must change our paradigm and shift our outlook on what it means to thrive and how we value others.”

-James Murtha, Former RAISE Council Member

# 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](#)

[Support Caregiving.org](#)



# What's Next?

- New ACL Initiatives to Support Implementation of the Strategy
  - National Caregiver Support Collaborative (NCSC)
  - Lifespan Respite Program Grants
  - New Alzheimer's Disease Program Initiative (ADPI) Respite Demonstration
  - Community Care Corps Program
  - Kinship and Grandfamily Support Network
  - Bridging Aging and Disability Networks
- 2024 Joint RAISE/SGRG Council Updated Report
- Early 2025 (tentative): Updated National Strategy to Support Family Caregivers

*We now have an unprecedented opportunity to achieve – and go far beyond – the goals Congress established in the RAISE Family Caregivers Act*

-Alison Barkoff, 2021



Thank you!