

# The RAISE Act and the National Strategy to Support Family Caregivers

A Presentation for the Federal Advisory Committee on  
Interdisciplinary, Community-Based Linkages

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# The Bottom Line

*Family caregiving is an issue that touches nearly every one of us in some way. Supporting the nation's 53 million family caregivers and 2.5 million grandparents raising grandchildren is critical. Successful development and implementation of a **National Family Caregiving Strategy** will require a coordinated, “all hands on deck” approach.*


# Family Caregiving: The Numbers

- Nearly one in five (53 million) adults provides care to a family member or friend
  - Twenty-four percent care for more than one person
  - Twenty-six percent have difficulty coordinating care\*
- Nearly 2.5 million grandparents raising grandchildren
  - 56% of grandparents are age 30-59
  - More prevalent in ethnic/culturally diverse populations†

Sources: \* [2020 Caregiving in the U.S. NAC/AARP](#)

† 2019 American Community Survey Data

# 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

# Casting a Wide Net

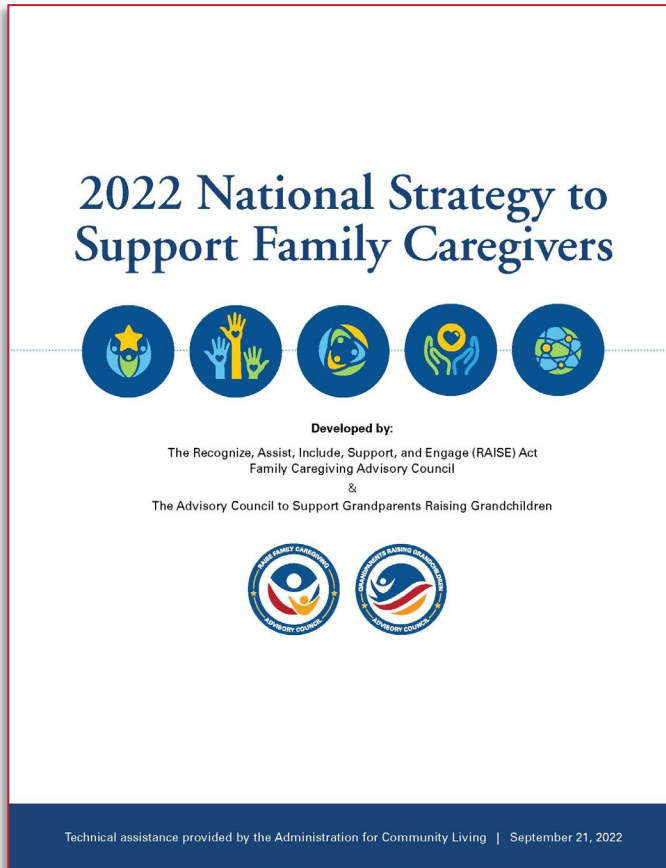
## Public Engagement

- 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

# 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



# A Driver for Legislative, Policy, and Practice Change

- Caregiver support and infrastructure development planning
  - Funding streams and funding levels
  - More universal adoption of caregiver assessments
  - Expansion of LTSS options to include family caregivers
  - Strengthen the direct care workforce
  - Address the issues impacting family caregivers, including:
    - Expand availability of services and supports in key benefit programs
    - Employment and employer concerns
    - Negative financial impacts
    - Greater and more meaningful inclusion as *care partners*, where appropriate and desired
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# Family Caregivers as *Care Partners*

## **Family Caregivers Can...**

- Help navigate fragmented, complex systems of care
- Serve as de facto care coordinators
- Support or make treatment decisions
- Actually perform many complex medical tasks

## **But They Are Often...**

- Excluded from care planning and related discussions
- Rarely considered or consulted when changes to the systems they must navigate are being considered
- Not assessed for their own training and support needs

# Supporting Family Caregivers as *Care Partners*

- Medical and healthcare providers can:
  - Adopt systems that allow family caregivers and other members of the care team to communicate directly and easily (with the approval of the care recipient).
  - Champion the inclusion of caregivers in existing processes and protocols, by:
    - Include families in the care process sooner
    - Develop job aids for health care professionals and discharge planners to integrate self-care for the family caregiver into a patient's care plan
    - Have dedicated staff for family caregiver engagement (caregiver engagement specialists).
    - Assess family caregiver needs.
  - Partner with caregiver CBOs, such as AAAs, ADRCs, State Councils on Developmental Disabilities, and Centers for Independent Living to support family caregiver needs by assessing referral systems for caregiver inclusion.

# 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](#)



Thank you