

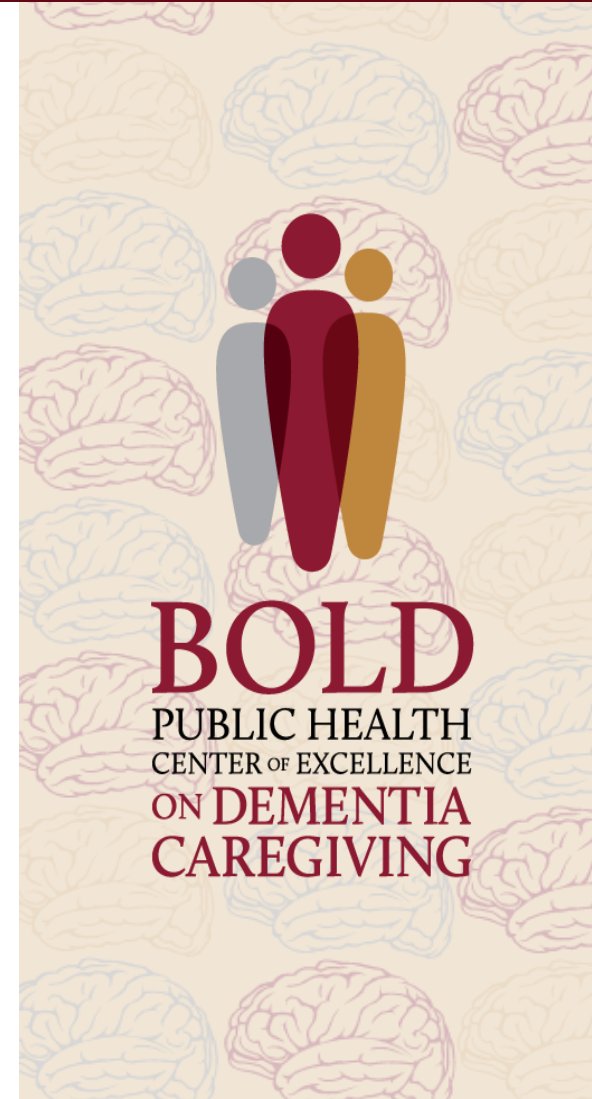
Overview of the RAISE Act and work of the Family Caregiving Advisory Council

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Family Caregiver





RECOGNIZE, ASSIST, INCLUDE, SUPPORT, & ENGAGE (RAISE) FAMILY CAREGIVERS ACT

Overview of the RAISE Act and work of the Family Caregiving Advisory Council

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Disclaimer

Opinions expressed within the context of this presentation are solely that of Alan B. Stevens, PhD, Co-Chair of the RAISE Family Caregiving Advisory Council (FCAC) and do not reflect the official opinions of the FCAC or the Administration for Community Living

Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act of 2017 (Signed into law 1/22/18)

- Family Caregiving Advisory Council
- Report to Congress
- National Family Caregiving Strategy



RAISE Family Caregiving Advisory Council
Administration for Community Living

- Ex-officio federal members
- 15 Non-federal voting members, 3 year terms
- *New non-federal voting members will be named in July, 2022*
- acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council

RAISE Family Caregivers Act

Family Caregiver – *“The term ‘family caregiver’ means an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation”*

RAISE Family Caregivers Act


Initial Report to Congress Delivered on September 22, 2021

- Identification of challenges faced by family caregivers and existing approaches to address such challenges.
- Overview of federally funded efforts to address those challenges.
- Some discussion of how Medicare and States' Medicaid programs address issues associated with family caregiving
- Recommendations to serve as a road map to the National Family Caregiving Strategy

acl.gov/RAISE/report



Reflects the Concerns of Caregivers Nationwide



★ ★

“ I’m not a stranger to hardship. My husband was a career marine and was often gone when our children were young. Our son requires 24/7 nursing, and it was difficult to find ethical and trained nurses. Sometimes he was harmed through negligence, causing more surgeries. ”


Debbi | Eagan, MN



★ ★

“ I felt the need to protect my wife while she wanted to maintain her independence, and we’ve achieved a balance where I trust her to ask for help when she needs it. ”

Leslie | Vancouver, WA



★ ★

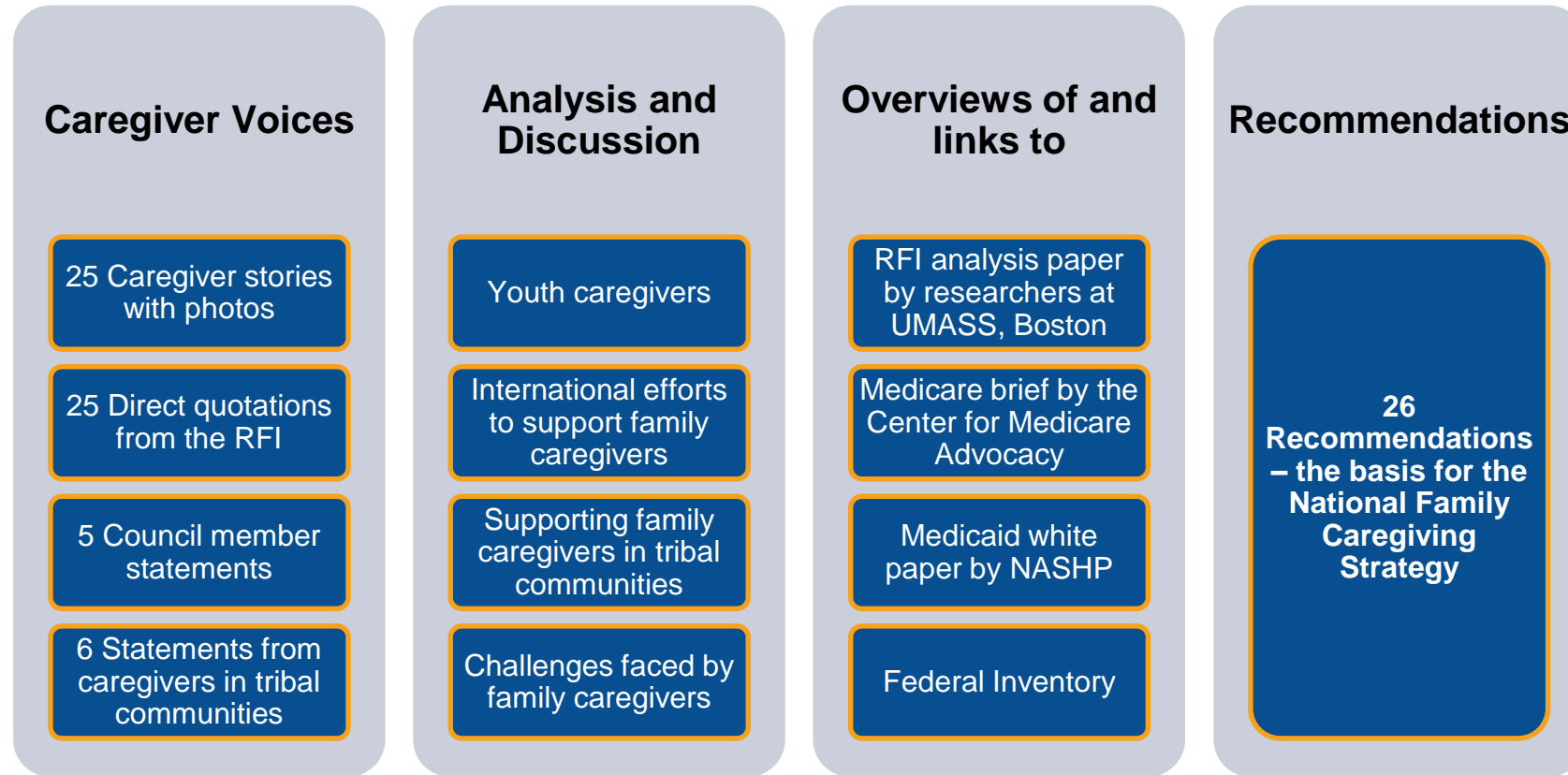
“ Caregivers run and run – they never know where the finish line is. I feel the hardest part of being a caregiver is learning how to be a caregiver. ”

TeriLynne | Maricopa, AZ

- 1,600 RFI responses (75% from caregivers)
- Caregiver focus groups

- Stakeholder listening sessions
- 25 caregiver narratives & videos

Comprehensive Analysis of Caregiving Landscape



“As a nurse and palliative care scholar, I have the knowledge and skills to manage the most complex of patient situations. Yet, the moment I became a family caregiver for my parents, I had no idea what to do.”

-Casey Shillam, family caregiver & Family Caregiving Advisory Council Co-chair

FCAC Adopted Recommendations Set the Course for the Initial Report to Congress

- Five Priority (goal) Areas
 - Awareness and Outreach for Family caregivers
 - Engagement of Family Caregivers as Partners in Healthcare and Long-Term Services and Supports
 - Services and Supports for Family Caregivers
 - Financial and Workplace Security for Family Caregivers
 - Research, Data and Evidence-Informed Practices
- 26 Recommendations to serve as the foundation for the National Family Caregiving Strategy

Awareness and Outreach for Family Caregivers

Goal 1: Family caregivers' physical, emotional, and financial well-being will improve as a result of expanded awareness, outreach, and education.

- 1.1:** Increase public awareness and recognition of the diverse needs, issues, and challenges family caregivers face and of the importance of recognizing and supporting them.
- 1.2:** Increase family caregivers' self-identification and awareness of, and access to, information, services, and supports across a range of topics.
- 1.3:** Improve outreach efforts to family caregivers to ensure early identification and access to services and supports.
- 1.4:** Support the development, or revision of, state, territorial, tribal and local planning that focuses specifically on recognizing, including, and supporting family caregivers of all ages and is aligned with the National Family Caregiving Strategy.
- 1.5:** Promote the expansion and role of public/private partnerships at all levels that recognize, assist, include, support and engage family caregivers.

Engagement of Family Caregivers as Partners in Healthcare and Long-Term Services and Supports

Goal 2: Family caregivers are recognized, engaged, and supported as key partners with providers of healthcare and long-term services and supports

- 2.1: Ensure the impact of policy and practices on family caregivers are studied and understood before changes are made in healthcare systems.
- 2.2:** Identify and include family caregivers as essential members and partners in the care recipient's care team.
- 2.3:** Engage family caregivers through the use of evidence supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support.
- 2.4:** Increase the integration of care through the inclusion of family caregivers in all relevant care coordination and transitions across providers and settings and when desired by both caregiver and care recipient.
- 2.5: Strengthen the training of healthcare, social service, and allied professionals to maximize family caregiver engagement and referrals to services in the community.

Services and Supports for Family Caregivers

Goal 3: Family caregiver have access to an array of flexible person- and family centered programs, supports, goods and services that meet the diverse and dynamic needs of family caregivers and care recipients.

- 3.1:** Increase access to meaningful and culturally relevant information, services, and supports for family caregivers.
- 3.2: Increase the availability of high-quality, setting appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities.
- 3.3: Increase the availability of diverse counseling, training, peer support, and education opportunities for family caregivers, including evidence-informed interventions.
- 3.4:** Expand caregiver support programs and services that maintain the health and independence of families by increasing access to housing, safe living accommodations, food, and transportation, and by reducing social isolation.

Services and Supports for Family Caregivers

Goal 3: Family caregiver have access to an array of flexible person- and family centered programs, supports, goods and services that meet the diverse and dynamic needs of family caregivers and care recipients.

3.5: Encourage use of technology solutions as a means of supporting family caregivers.

3.6: Expand the use of vetted volunteers and volunteerism as a means of supporting family caregivers.

3.7: Improve the support of family caregivers during emergencies (e.g., pandemics, natural/manmade disasters).

3.8: Increase the prevalence and use of future planning as a means for ensuring family members have the needed supports in place throughout the care recipient's life.

3.9: Increase and strengthen the paid LTSS and direct support workforce.

Financial and Workplace Security for Family Caregivers

Goal 4: Family caregivers' lifetime financial and employment security is protected and enhanced.

4.1: Decrease the negative financial impacts for family caregivers on both a short- and long-term basis.

4.2: Advance the development and broad adoption of employee-centered flexible workplace policies and practices that support work/life balance and maintain performance when personal circumstances change.

4.3: Increase the availability, and use of, financial education and planning tools for family caregivers.

4.4: Improve the affordability of long-term services and supports and reduce out-of-pocket costs for families through public and private payers.

Research, Data, and Evidence-Informed Practices

Goal 5: Family caregivers are engaged stakeholders in a national research and data gathering infrastructure that documents their experiences, translates evidence into best practices, develops person- and family-centered interventions, and measures progress toward the National Family Caregiver Strategy.

- 5.1:** Establish a national infrastructure using standardized data, questions, and a definition of “family caregiver” for obtaining, analyzing, and disseminating information about caregivers and their experiences.
- 5.2:** Increase family caregiver research that facilitates the development and delivery of programs and services that support and enhance the health and well-being of the caregiver and care recipient.
- 5.3:** Increase the promotion, translation, and dissemination of promising and evidence-supported practices to support family caregivers in the delivery of healthcare and long-term services and supports.

RAISE Family Caregiver Act

The National Family Caregiving Strategy

The Strategy will provide a national roadmap towards greater recognition, assistance, inclusion, support, and engagement of family caregivers

- The 26 recommendations provide the foundation for *the Strategy*
- Engagement of federal & state agencies, and the public continues
- *The Strategy* will identify actions that the federal government along with states, local communities, health and LTSS providers, and others can take to recognize and support family caregivers.

RAISE Family Caregiver Act

The National Family Caregiving Strategy

The Strategy will be inclusive of specific actions leading to:

- Greater adoption of person- and family-centered care across settings
- More consistent assessment and service planning for family caregivers
- Better availability of information, education and training supports, referral and care coordination for family caregivers
- Improved respite options for family caregivers
- Financial and workplace security for family caregivers
- Caregiving support services based on performance, mission and purpose of a program with the aim of strengthening and eliminate redundancies of federal programs

RAISE Family Caregiver Act

The National Family Caregiving Strategy

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



Faces of RAISE

#RAISEcaregiving

RAISE Family Caregivers Advisory Council



The
John A. Hartford
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[ACL.gov/RAISE](https://acl.gov/RAISE) #RAISECaregiving