

The RAISE Act & National Family Caregiving Strategy: A Roadmap for Change

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May 16, 2022



Family Caregivers: In their own words...

- “When you’re starting the journey, you don’t have enough knowledge to know what you need.”
- “It would have been immensely helpful to just hear other people and know that I’m not alone in this.”
- “Nobody ever taught me how to do the medical portion of taking care of my son . . . It can be scary. I wish someone like a nurse . . . could have spent more time teaching me how to use his medical equipment.”



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.*

The Administration for Community Living

ACL's Mission

Maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers

ACL's Vision

For all people, regardless of age and disability, to live with dignity, make their own choices, and participate fully in society. Therefore, we will:

- Promote strategies that enable people to live in their communities
- Provide leadership and support
- Be a source of collaboration, innovation, & solutions
- Support employee contributions, professional growth, and work-life balance
- Be effective stewards of public resources and a source for information

The RAISE Act: Nuts & Bolts

- Became law: Jan 22, 2018
- Three key components:
 - Family Caregiving Advisory Council
 - Initial Report to Congress
 - National Family Caregiving Strategy
- Current sunset: January 2022
- Ongoing appropriations

The Importance of Partnerships

- The John A. Hartford Foundation
 - History of supporting ACL's efforts
 - Projects of national scope
 - Collaborated with ACL to develop concept for the RAISE Resource and Dissemination Center at NASHP
- National Academy for State Health Policy (NASHP)
 - National Alliance for Caregiving
 - UMass Boston
 - Community Catalyst
- [The RAISE Family Caregiver Resource and Dissemination Center](#)

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
- 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

The Initial Report to Congress



- Delivered to Congress on 9/22/21
- Disseminated publicly on 9/23/21
- Caregiver “stories”
- Focused look at Medicare, Medicaid, and tribal concerns
- 26 recommendations for action

The National Family Caregiving Strategy

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

The National Family Caregiving Strategy

- The Strategy must:
 - Be developed jointly by Federal agencies and the FCAC
 - Include actions Federal, state, local, communities, health and LTSS providers and others can take to recognize and support family caregivers (i.e., a *National* strategy)
 - Reflect the diverse needs of family caregivers
 - Be submitted to Congress and made available online
 - and.....

The National Family Caregiving Strategy

When complete later this year, seek to eliminate redundancies and “promote greater adoption of”:

- Person- and family-centered care across settings
- Assessment and service planning
- Information, education and training supports, referral and care coordination
- Respite options
- Financial security and workplace issues
- Service delivery based on performance, mission, and purpose of a program

The National Family Caregiving Strategy: Structure & Content

- **Narrative & framing**
 - Background and context
 - Recommendations re-framed as outcomes
- **Federal actions to support family caregivers**
 - 14 agencies contributed over 350 separate actions
 - Near, mid- and long-term actions
- **Other sector actions**
 - States, communities, health/LTSS, employers, researchers, faith, schools, etc.
 - A “roadmap” for the country
- And....

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



The Time is Now...

If family caregiving can be...

- Anxiety-producing
- Empowering
- Overwhelming
- Meaningful
- Exhausting
- Gratifying
- Lonely
- Hopeful

Then a National Family Caregiving Strategy can...

- Elevate the conversation
- Re-frame the narrative
- Drive change and innovation
- Promote greater recognition and inclusion of family caregivers
- Be a tool for advocacy
- Guide program planning & policy development,
- Shape research



In their own words

“I'm glad that I had the means to be able to do it the way that I did, and still there's so much that we lost because of how little real support is at a societal level that I had.”

“You're [going to] get sick, your family members are [going to] get sick, your kids might get sick, that is a given, so given that that's going to happen, why do we not have a solution for how to help people?”

Abena, Family Caregiver, Washington D.C., Page 60

Thank You!