

RAISE Family Caregivers Act:

Progress Toward a National Strategy to Support Family Caregivers

Administration for Community Living
RAISE Family Caregiving Advisory Council
Progress Report



TABLE OF CONTENTS

Introduction	2
The RAISE Family Caregivers Act.....	2
Progress Report.....	3
Selection of the Family Caregiving Advisory Council	3
The RAISE Act Family Caregiver Resource and Dissemination Center	4
Convening the Family Caregiving Advisory Council.....	4
Second Full Council meeting	5
Next Steps	6
Public Input	6
Inventory of Federal Efforts to Support Family Caregivers.....	6
Authors	7

INTRODUCTION

In 2017, an estimated 41 million family caregivers in the United States provided 34 billion hours of care to adults with chronic health conditions or disabilities.ⁱ This is in addition to the millions of parents who care for children with disabilities or chronic illness.

This estimate isn't surprising. Family caregivers, who have historically assisted with household tasks and personal care, are increasingly called on to provide medical and complex care at home (care provided by trained health care professionals in the past), while also navigating insurance and health care systems. These time-intensive and demanding responsibilities are often complicated by additional barriers including privacy requirements of HIPAA (Health Insurance Portability and Accountability Act), health care delivery models that do not include family caregivers, and the inability for providers to bill for time spent with caregivers. These difficulties may be exacerbated for diverse populations that experience disproportional problems with access or communication.

Given the critical role caregivers play in the health and well-being of individuals across the lifespan, caregiving has become increasingly present within federal and state health policies over the last two decades. A key exemplar of bipartisan commitment to supporting family caregivers is the Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017 (RAISE Family Caregivers Act).

The RAISE Family Caregivers Act

The RAISE Family Caregivers Act, which became law on Jan. 22, 2018, directs the Secretary of Health and Human Services to develop a national family caregiving strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers.

To support the development and execution of the strategy, the RAISE Act also requires establishment of a Family Caregiving Advisory Council to provide advice and recommendations and identify best practices for recognizing and supporting family caregivers. The legislation defines "family caregiver" as *"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."*

The [Administration for Community Living](#) (ACL) is leading the Department of Health and Human Services' efforts around this council.

The legislation required that the council include up to 15 voting members, with at least one from each of the following constituencies: family caregivers; older adults who need long-term services and supports; individuals with disabilities; health care and social service providers; providers of long-term services and supports; employers; paraprofessional workers; state and

local officials; accreditation bodies; veterans; and as appropriate, other experts and advocacy organizations engaged in family caregiving.

The voting members reflect the diversity of caregivers and individuals receiving long-term services and supports (LTSS) as well as non-voting members from federal departments and agencies that play a role in these issues. The council must meet quarterly in the year from the date of enactment, and at least three times annually thereafter.

The council is tasked with creating and submitting an initial report and biennial updates thereafter. The preliminary report will include an inventory of federally funded efforts to support caregivers and recommendations to improve these efforts and effectively deliver services based on the performance, mission, and purpose of a program. The goal of this inventory is to highlight areas of overlap as well as gaps in federal programs that support caregivers. The initial report will also review the financial, social, and emotional challenges of caregiving and the impact of caregiving on Medicare and Medicaid.

The *National Family Caregiving Strategy* will be developed by the Secretary of Health and Human Services, the council, and heads of other federal agencies. The strategy shall identify recommended actions that federal, state, and local governments; communities; and health and LTSS providers can take to support family caregivers with diverse needs.

The following is an update on progress since enactment of the RAISE Family Caregivers Act.

PROGRESS REPORT

Selection of the Family Caregiving Advisory Council

ACL published a Federal Register Notice on October 12, 2018 calling for nominations for non-federal members to serve on the council. ACL received more than 270 unique nominations for individuals to serve on the council. ACL staff reviewed each submission and narrowed the field of proposed nominees. In selecting the nominees, the following factors were considered:

1. Experience and qualifications: Each nomination represented different experiences and qualifications. Every effort was made to identify the experiences and expertise that would ensure a council membership with a robust and diverse background and perspective on caregiving.
2. Geographic and regional distribution: The experiences of caregivers, older adults and persons with disabilities, and the professionals who work in this arena can vary by state/region, as can the resources and programs available to support them. The nominees reflected a cross-section of the nation.
3. Letters of support: Many of the nominations included letters of support and reference from legislators, co-workers, employers, etc. These letters were used to support ACL's recommendation to nominate.

The RAISE Act Family Caregiver Resource and Dissemination Center

In May 2019, The John A. Hartford Foundation awarded a three-year grant to the National Academy for State Health Policy (NASHP) to support the efforts of the council. The grant established NASHP's [RAISE Act Family Caregiver Resource and Dissemination Center](#) as a national focal point for resources, technical assistance, and policy analysis for states and the broader stakeholder caregiver community.

The goals of the dissemination center include: development of family caregiving resources for state and federal policymakers and other stakeholders; technical support for the council and subcommittees as they craft policy recommendations; opportunities for experts and thought leaders to provide perspectives and expertise to the council; and assistance to states as they develop policies to address family caregiver issues.

NASHP created a [faculty of experts](#) in the field to inform the work of the center and the council. The faculty represents a wide range of thought leaders from family caregiving organizations, academic institutions, and state administrations.

Convening the Family Caregiving Advisory Council

On August 28th and 29th, 2019, the council convened for the first time in Washington, DC. The inaugural meeting included remarks from Lance Robertson, Administrator and Assistant Secretary of Aging at ACL, and Eric Hargan, Deputy Secretary of the Department of Health and Human Services, both of whom emphasized the importance of the council's work. Throughout the first day, speakers shared results and strategies from advocacy efforts, national research, and state-driven task forces. Common among all presentations were the following threads: the importance of recognizing the diversity of needs among caregivers and care recipients; supporting the wellbeing of family caregivers and care recipients; and integrating family caregivers into--and empowering them within--the healthcare system. The council's members broke into three subcommittees for smaller group discussion.

Subcommittee 1: Assist Caregivers in Optimizing Care and Support for their Loved Ones. This subcommittee will prioritize caregiver empowerment through resource identification and access as well as efforts to promote and support development of a workforce with the capacity to support family caregivers and individuals requiring care.

Subcommittee 2: Enable Caregivers to Provide Care While Maintaining their Health and Well-Being. This subcommittee will look at access to services and supports that contribute to a plan of care and support for family caregivers as well as ways to increase/improve the capacity to meet family caregiver needs. Notably, these priorities will take a lifespan approach, assessing the continuum of care across the life course. This subcommittee will focus on short-term and long-term workforce development and financial considerations of care and increasing available resources and services and uptake of evidence-based practices.

Subcommittee 3: Enhance Public Awareness and Education and Engage Non-governmental Entities to Support Caregivers. This subcommittee will focus on making the case to multiple audiences for the value of family caregivers and identifying and engaging traditional and non-traditional partners in family caregiver support.

Since the inaugural meeting, the subcommittees have been meeting regularly to discuss and make action plans for their priority areas. These subcommittee meetings have been facilitated by ACL and NASHP.

Second Full Council meeting

On February 11 and 12, 2020, the council convened for the second time, this time virtually. At this meeting, the council formed guiding principles and goals and established procedures for obtaining public input. The council developed the following guiding principles, as a framework for the national strategy:

- “Family caregiver” is an inclusive and holistic term that includes all who are caring for individuals across the life span who have chronic or other health conditions, disabilities, or functional limitations.
- Person- and family-centered care involves putting the person and family at the center of care teams, and this approach should be promoted while acknowledging the challenges of possible conflicting goals.
- Efforts to support family caregivers should advance the autonomy, choice, and ability of caregivers and care recipients to engage meaningfully in their communities.
- Recommendations should recognize and support family caregivers in a fair and impartial manner that respects and appreciates their complexity, diversity, and dignity and accounts for the financial impact on families.
- The national strategy, created in partnership with family caregivers, will be a living document that fosters cross-discipline and cross-sector collaboration and outlines ongoing actions to be taken by federal, state, and local governments, communities, providers, and others.

The council developed primary goals for its recommendations to Congress:

- Expand awareness, outreach, education, and access for programs, services, and products to optimize the physical, emotional, and financial well-being of family caregivers and care recipients;
- Recognize, include, and support family caregivers as key partners in the provision of health care and long-term services and supports;
- Protect, promote, and enhance financial and workplace security of family caregivers;
- Promote research, identification, and adoption of evidence-based practices in caregiver support; and

- Strengthen program administration, governance, and collaboration among all appropriate stakeholders to build a society that recognizes family caregivers.

NEXT STEPS

The council is moving forward with great enthusiasm and momentum. In 2020, The council will focus on developing the national strategy and delivering its initial report to Congress. The following activities will support this effort.

Public Input

The council called on the public to help inform the national strategy to support family caregivers. In December 2019, ACL issued a Request for Information (RFI) that received more than 1,600 responses before it closed on February 7, 2020. The information contained in the responses will be used to: (1) assist The Council in formulating goals, objectives, and recommendations in support of the initial report to Congress and development of the national caregiving strategy, and (2) inform public listening sessions.

As part of John A. Hartford Foundation's grant to NASHP, [the LTSS Center](#) (a joint venture among UMass Boston, Community Catalyst, and LeadingAge) was awarded a competitive contract to sort, categorize, and analyze information collected from the RFI. The center will also conduct 10 to 15 virtual and in-person listening sessions with stakeholders and members of the public in 2020. UMass will use the RFI to identify specific services, supports, or policy initiatives that meet the caregiving needs and can inform the development of federal, state, and community programs and services.

Detailed analysis of the RFI will be presented to the council for its consideration and prioritization to inform the initial report to Congress. Responses to the RFI will also be used to develop focus groups to gather more information. Currently, three in-person focus groups are planned, one in the metropolitan DC area and two in the Boston area. One focus group in the Boston area will be conducted in Spanish.

Inventory of Federal Efforts to Support Family Caregivers

To support the council's recommendations, ACL is currently conducting an inventory and assessment of all federally funded efforts to recognize and support family caregivers and the outcomes of such efforts. This inventory will include analyses of which federally funded efforts are reaching family caregivers as well as gaps in such efforts, as required by the legislation.

Although the council members have been thoughtfully, diligently, and thoroughly fulfilling the requirements of the RAISE Act, it is clear that this work has only just begun. The investment and commitment of policymakers, advocacy organizations, as well as the continuous input from the public, are critical to the success of this legislation. Members of the public can follow the council's continued progress at [raisefamilycaregiving.org](https://www.raisefamilycaregiving.org), which is updated regularly to include full council meeting notes, streaming, and resources.

AUTHORS

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ENDNOTE

¹ Reinhard S, Feinberg LF, Houser A, Choula R, Evans M. Valuing the Invaluable: 2019 Update Charting a Path Forward. AARP Public Policy Institute; 2019. <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>.