

Implementing the RAISE Family Caregivers Act

The [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregivers Act of 2017](#), was signed into law in January 2018. It seeks to address the diverse and complex issues faced by family caregivers through the development of a National Family Caregiving Strategy. The RAISE Act consists of three key elements: the formation of the nation's first Family Caregiving Advisory Council; the development of a Report to Congress; and the creation of National Family Caregiving Strategy.

The Family Caregiving Advisory Council

To form the council, ACL issued a call for nominations in the Federal Register in October 2018; 270 unique nominations were received. In selecting the nominees for appointment, ACL weighed breadth of experience, qualifications, and geographic and regional distribution to ensure the council reflected the dynamic nature of the family caregiving landscape. Of the council members selected, many are—or have been—either caregivers, people receiving support—or both.

In August 2019, the council convened in Washington, D.C. During the meeting—and subsequent in-person and virtual meetings—council members and guest speakers shared and discussed personal stories, results, and strategies from advocacy efforts, and findings of national research and state-driven task forces. Throughout 2020 and 2021, the council conducted substantive deliberations—moving to an online platform during the COVID-19 pandemic. Inherent in the council's work was a focus on balancing the perspectives and needs of caregivers of older adults with those of care partners and family members of people with disabilities.

Over the course of their deliberations, the council identified several unifying characteristics of family caregivers that

must be acknowledged as we look for more holistic ways of supporting them:

1. A **significant personal relationship** or connection often exists between family caregivers and the people who receive support. Some caregivers provide assistance out of a wellspring of love and concern, but personal feelings are not always the driving force. Other caregivers provide care in response to tradition, culture, family expectation, and other factors. Often some combination of these reasons shapes the experience of family caregivers.
2. Many family caregivers are driven by the desire **to help maintain the independence, dignity, engagement, and/or quality of life** of the person they are supporting.
3. Caregivers often **provide support without a formal assessment** of their needs or of the person receiving support. They often learn “on the job,” taking on tasks they do not know how to do, or do not feel comfortable doing, and have little access to training or assistance. Further, there is little recognition of the difficulty of their responsibilities.
4. The nature of **family caregiving is becoming ever more complex** in the modern era as it extends to more medical, administrative, and care coordination activities than ever before. Caregiving today can include complex medication management, dealing with insurance payers, operating electronic equipment and medical devices, and coordinating care across systems.
5. No matter how emotionally rewarding, caregiving can leave caregivers **financially, emotionally, and physically depleted, and socially isolated**.

The Initial Report to Congress

The council's initial Report to Congress addresses each of the topic areas specified by Congress in the RAISE Act, and includes:

- » The identification of challenges faced by family caregivers, including financial, health, and other challenges, and existing approaches to address such challenges.
- » An overview of federally funded efforts to address those challenges.
- » A discussion of how family caregiving impacts the Medicare program, the Medicaid program, and other federal programs.
- » Recommendations to improve and better coordinate federal programs and activities to recognize and support family caregivers and improve the coordination of such federal programs and activities with state programs and other programs.

In addition to surveying existing literature, programs, and data about family caregiving, and with generous support made possible by an innovative [public-private partnership](#), the council undertook a broad effort to engage the public for input to the report. Those efforts included a widely disseminated Request for Information (RFI) in 2019, listening sessions, focus groups, and interviews with 25 family caregivers whose stories and words are presented throughout the report.

In November 2020, the council adopted 26 recommendations to improve and better coordinate federal, state, tribal, and community programs and activities to recognize and support family caregivers. These recommendations are the framework of the forthcoming National Family Caregiving Strategy. They cover a range of critical issues the nation must address in bold and meaningful ways in order to demonstrate that it values the contributions of family caregivers.

Looking Ahead: The National Family Caregiving Strategy

The RAISE Act is specific in its requirements for the scope of the National Family Caregiving Strategy. Using the 26 recommendations, and through further engagement with the public, the council will next turn its efforts to developing the Strategy. With the Act as a framework, 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.

Like the Report to Congress, the Strategy will reflect the diverse needs and preferences of family caregivers and will include actions the nation can take to better-support family caregivers using family-centered approaches; assessment and service planning; greater respite options; more options for information, education, and training supports; strengthening financial security and addressing workplace issues; and fostering improvements in service delivery. When completed, the Strategy will provide a national roadmap towards greater recognition, assistance, inclusion, support, and engagement of family caregivers.

Learn more about the RAISE Family Caregivers Act and the Advisory Council at [ACL.gov/RAISE](https://acl.gov/RAISE).

