

Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act



Family caregivers are the most important source of support for people with chronic or other health conditions, disabilities, or functional limitations. Millions of family caregivers help their loved ones live at home and in their communities, providing the bulk of this assistance. In 2013, about 40 million family caregivers provided unpaid care valued at about \$470 billion to adults who needed help with daily activities such as bathing, dressing, meal preparation, and transportation, more than total Medicaid spending that year.¹ According to *Caregiving in the US 2015*, about 3.7 million family caregivers provided care to a child under age 18 because of a medical, behavioral, or other condition or disability and 6.5 million family caregivers assisted both adults and children.² Estimates show 3.5 million individuals with intellectual or developmental disabilities (I/DD) live with family caregivers, of whom over 850,000 are age 60+.³

What do family caregivers do?

Family caregivers help with activities such as eating, bathing, dressing, transportation, and managing finances; perform medical/nursing tasks such as wound care and managing multiple, complex medications; arrange and coordinate care among multiple providers and settings; and pay for services to help their loved ones, such as home modifications, transportation, or a home care aide. The assistance family caregivers provide saves taxpayer dollars, helps to delay or prevent their loved ones from needing more costly nursing home care, and helps prevent unnecessary hospital readmissions. Family caregivers spend an average of 18 hours a week caring for their loved one;⁴ almost one-third of family caregivers provide an average of 62 hours of care a week.⁵

What challenges do family caregivers face?

Family caregivers take on physical, emotional, and financial challenges. They commonly experience emotional strain and mental health problems, especially depression, and have poorer physical health than noncaregivers.⁶ Family caregivers generally do not receive training and other assistance to help them provide care.⁷ Too often family caregivers aren't even recognized and included, as appropriate, by health care and social service providers helping their loved ones. Navigating, locating, and coordinating fragmented services is too often bewildering, complex, and very time consuming.

Most family caregivers are employed and juggle work and caregiving responsibilities. They often make workplace accommodations because of caregiving, up to and including leaving their jobs.⁸ Employers have an interest in supporting family caregiver employees so they do not lose talented workers. Family caregivers (age 50 and older) who leave the workforce to care for a parent lose, on average, nearly \$304,000 in wages and benefits over their lifetime. These estimates range from \$283,716 for men to \$324,044 for women.⁹ In addition, family caregivers may pay out-of-pocket for services whose costs add up over time.

Family caregivers will only face greater strains in the future as the “caregiver support ratio” – the number of potential family caregivers aged 45-64 for each person aged 80+ - shrinks. In 2010, the ratio was more than seven potential caregivers for every person in the high-risk years of 80-plus. By 2030, this ratio is projected to decline sharply to 4 to 1 and to less than 3 to 1 in 2050.¹⁰

Why is a national strategy to support family caregivers important?

If family caregivers were no longer available, the economic cost to the U.S. health care and long-term services and supports (LTSS) systems would increase astronomically. Our country relies on the contributions family caregivers make and should recognize and support them. Supporting family caregivers helps the caregivers themselves, the millions of individuals who rely on them, and also the economy and the workplaces who benefit from the contributions of family caregivers. AARP urges Congress to enact the **Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (S. 1719/H.R. 3099)** introduced by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI) and Representatives Gregg Harper (R-MS) and Kathy Castor (D-FL). This bill would implement the bipartisan recommendation of the federal Commission on Long-Term Care that Congress require the development of a national strategy to support family caregivers, similar in scope to the national strategy developed to address Alzheimer's disease.

What would the RAISE Family Caregivers Act do?

It would require the development, maintenance, and updating of an integrated national strategy to recognize and support family caregivers by the HHS Secretary. A family caregiver is a relative, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance for, a person with a chronic or other health condition, disability, or functional limitation. The bill would bring together relevant federal agencies and others from the private and public sectors, such as family caregivers, older adults and persons with disabilities, health care and LTSS providers, employers, relevant industries, state and local officials, and others on an advisory council to advise and make recommendations regarding the national strategy. The advisory council meetings would be open to the public and there would be opportunities for public input. The strategy would identify specific actions that government, communities, providers, employers, and others can take to recognize and support family caregivers, including with respect to:

- Promoting greater adoption of person-and family-centered care in all health and LTSS settings, with the person and the family caregiver (as appropriate) at the center of care teams;
- Assessment and service planning (including care transitions and coordination) involving care recipients and family caregivers;
- Training and other supports;
- Information, education, referral, and care coordination;
- Respite options;
- Financial security;
- Workplace policies and supports that allow family caregivers to remain in the workforce.

There would be 18 months for the development of the initial strategy, followed by annual updates of the strategy. The bill would improve the collection and sharing of information, including related to evidence-based or promising practices and innovative models regarding family caregiving; better coordinate, maximize the effectiveness, and avoid unnecessary duplication of federal government activities to recognize and support family caregivers; assess federal programs around family caregiving; and address disparities and meet the needs of the diverse caregiving population. The strategy and work around it could help support and inform state and local efforts to support family caregivers.

AARP urges Congress to enact the RAISE Family Caregivers Act to recognize, assist, include, support, and engage family caregivers! Sooner or later, we'll all be family caregivers or someone who needs one.

¹ S. Reinhard, L. Feinberg, R. Choula & A. Houser, *Valuing the Invaluable: 2015 Update, Undeniable Progress, but Big Gaps Remain* (AARP PPI, 2015), available at <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-undeniable-progress.pdf>.

² National Alliance for Caregiving (NAC) and AARP, *Caregiving in the U.S. 2015: Executive Summary*, (June 2015), available at http://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015/?cmp=CRGVNUSA_MAY21_015.

³ D. Braddock, Testimony before the Commission on Long-Term Care on *Summary of National Trends: 2013 The State of the States in Developmental Disabilities* (July 17, 2013) available at <http://ltccommission.lmp01.lucidus.net/wp-content/uploads/2013/12/TestimonyBraddock-LongTermCareCommission07-17-2013.pdf>.

⁴ S. Reinhard, L. Feinberg, R. Choula & A. Houser, *Valuing the Invaluable: 2015 Update, Undeniable Progress, but Big Gaps Remain* (AARP PPI, 2015).

⁵ National Alliance for Caregiving and AARP, *Caregiving in the US 2015: Executive Summary*, (June 2015).

⁶ L. Feinberg, S. Reinhard, A. Houser & R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving* (AARP PPI, 2011), available at <http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html>.

⁷ S. Reinhard, C. Levine & S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* (AARP PPI and United Hospital Fund, 2012), available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf.

⁸ L. Feinberg, S. Reinhard, A. Houser & R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving* (AARP PPI, 2011).

⁹ Data from MetLife Mature Market Institute, *The MetLife Study of Caregiving: Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring For Their Parents* (Westport, CT: MetLife Mature Market Institute, 2011), as cited in L. Feinberg & R. Choula, *Understanding the Impact of Family Caregiving on Work* (AARP PPI, 2012), available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf.

¹⁰ D. Redfoot, L. Feinberg, & A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (AARP PPI, 2013), available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf.