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# Families Caring for An Aging America

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Committee on Family Caregiving for Older Adults

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# Family Caregiving for Older Adults

- ❑ Although an intensely personal issue, family caregiving has become an urgent public policy issue, linked to important social, health, and economic goals
- ❑ Family caregivers provide the lion's share of long-term services and supports (LTSS) to older adults
- ❑ CBO estimates that the value of family caregiver's services to older adults was \$234 billion in 2011
- ❑ The committee's work calls into question practices that assume the availability of a family caregiver without adequate support services

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# Charge to the Committee

## Three primary objectives

- To assess the prevalence and nature of family caregiving of older adults
- To assess the impact of caregiving on individuals' health, employment, and overall well-being
- To recommend policies to address caregivers' needs and to help minimize the barriers that they encounter in acting on behalf of an older adult

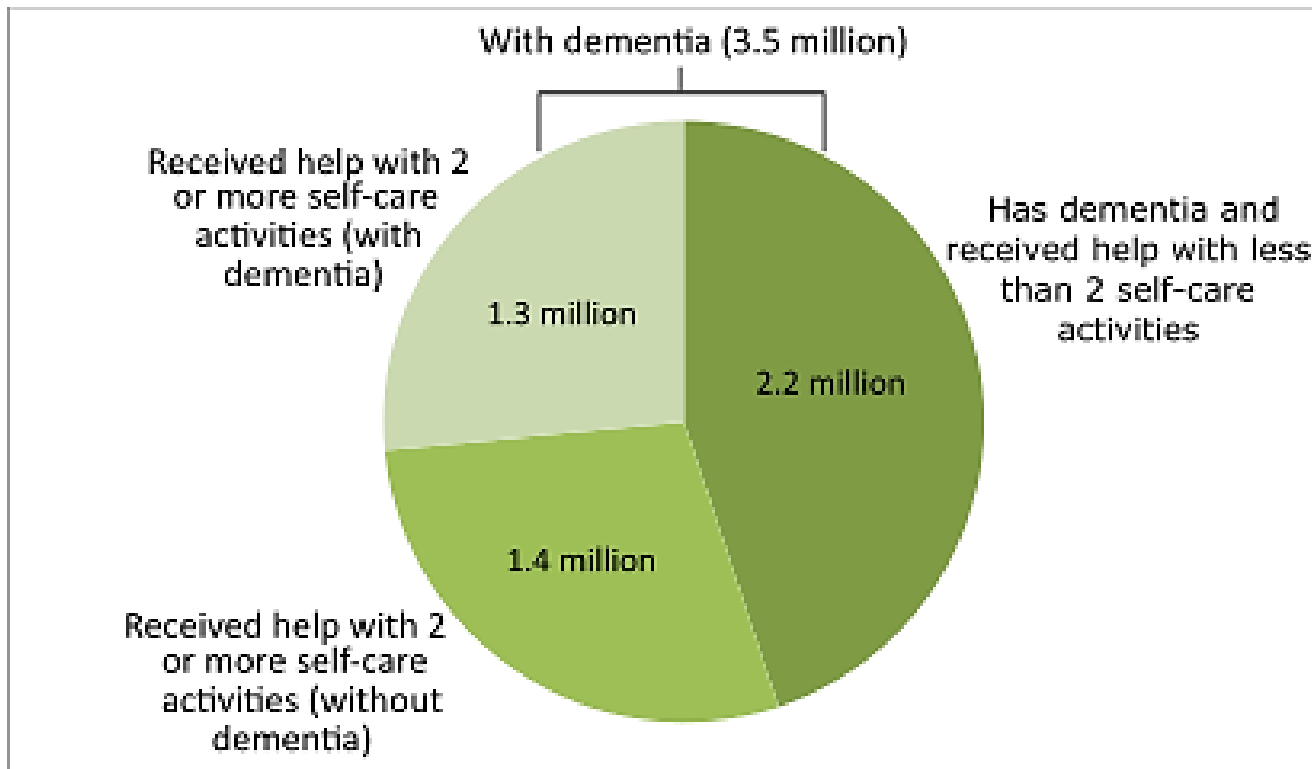
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# Rapidly rising numbers of older adults and fewer family caregivers to help them

- ❑ Historic demographic changes
  - In 2012, 43.1 million adults age 65+ (13.7% of U.S. population)
  - By 2030, 72.7 million adults age 65+ (>20% of U.S. population)
  - Increasing diversity but national surveys are not powered for subgroup analyses
- ❑ Fastest growing cohort of older adults are those age 80+
  - When people are most likely to have a physical or cognitive impairment
  - As a result, the demand for caregivers is growing rapidly
- ❑ The gap between the demand for and supply of family caregivers is increasing
  - The size of American families is shrinking and the makeup of families is changing

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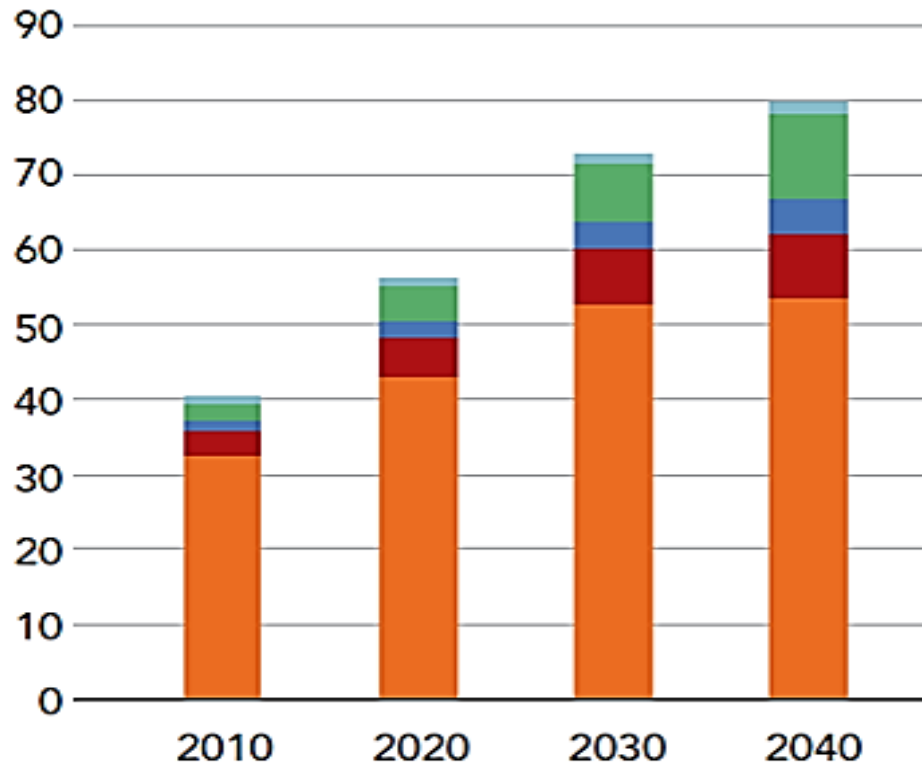


## 8.5 million caregivers provide help to 4.9 million high-need older adults (persons with dementia and/or 2 or more self-care needs), 2011

NOTES: As reported by Medicare beneficiaries age 65 and older (or their proxy) for the prior month. Self-care activities include bathing, dressing, eating, toileting, or getting in and out of bed. “Probable dementia” includes individuals whose doctor said they had dementia or Alzheimer’s disease and individuals classified as having probable dementia based on results from a proxy screening instrument and several cognitive tests. Excludes nursing home residents.

SOURCE: Data from the 2011 NHATS.

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**Changing racial and ethnic diversity, U.S. older adults, 2010 to 2040 (in millions)**

SOURCE: Adapted from Frey, 2014

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# Older adults' need for help varies widely

- ❑ The care older adults need may be episodic, daily, occasional, short- or long-term
  - About 6.3 million older adults receive a family caregiver's help with household tasks or self-care because of health or functioning reasons (2011)
  - An additional 3.5 million older adults receive help because they have dementia (2011)
  - 1.1 million reside in nursing homes (2011) but there are very limited data on their family caregivers
  - Some need short-term help after a hospital stay or non-catastrophic injury; others will never need a caregiver's help
- ❑ At least 17.7 million individuals are family caregivers (relatives, partners, friends, or neighbors who assist someone age 65+ with physical, mental, cognitive, or functional limitations) (2011)

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# Average Number of Years Caregivers of Older Adults Spend Caregiving

Years	Percent of Caregivers
1 year or less	15.3%
2 to 4 years	34.7
5 to 10 years	34.9
More than 10 years	15.1

NOTE: Includes family caregivers of Medicare beneficiaries age 65 and older in the continental United States who resided in community or residential care settings (other than nursing homes) and received help with self-care, mobility or household activities for health or functioning reasons. Respondents were asked “How many years have you been helping the care recipient?” Responses were given in whole numbers.

SOURCE: Data from the 2011 NHATS and the companion NSOC.

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# The family caregiver role is far more complex and demanding than in the past

- ❑ Family caregivers have always been the primary providers of older adults' long-term services and supports such as:
  - Household tasks and self-care (getting in and out of bed, bathing, dressing, eating, or toileting)
- ❑ Today, they are also tasked with managing difficult medical procedures and equipment in older adults' homes, overseeing medications, and monitoring symptoms and side effects, and navigating complex health and LTSS systems
  - Including health care services that, in the past, were delivered only by licensed health care personnel (injections, IVs)
  - And, often, without training, needed information, or supportive services

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# The health impact of caregiving is highly individual and dependent on personal and family circumstances

- ❑ For some, caregiving instills confidence, provides meaning and purpose, enhances skills, and brings the caregiver closer to the older adult.
- ❑ For others, caregiving leads to emotional distress, depression, anxiety, and impaired physical well-being.
- ❑ The intensity and duration of caregiving and the older adult's level of impairment are predictors of adverse consequences.
  - Family caregivers spending long hours caring for someone with advanced dementia are especially vulnerable
  - Other risk factors are low socioeconomic status, high levels of perceived suffering of the care recipient, living with the care recipient, lack of choice in taking on the caregiving role, poor physical health, lack of social support, and a physical home environment that makes care tasks difficult

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# Family caregiving of older adults poses substantial financial risks for some caregivers

- ❑ Family caregivers of older adults with significant cognitive or physical impairments are at the greatest risk of financial harm
  - Especially if they are low-income, have limited financial resources, reside with or live far from the care recipient, or have limited or no access to paid leave (if they are employed)
- ❑ They may lose income, Social Security and other retirement benefits, and career opportunities if they have to cut back on work hours or leave the workforce
- ❑ They may also incur substantial out-of-pocket expenses that undermine their own future financial security.

# Many employed family caregivers do *not* have unpaid or paid leave benefits at work

- ❑ More than half of family caregivers are employed either part- or full-time
- ❑ Daughters- and sons-in-law, stepchildren, grandchildren, and siblings of older adults are not eligible for the unpaid protections of the Family and Medical Leave Act (FMLA) nor are employees of small firms
- ❑ Federal, state, and municipal laws provide some protections for employed family caregivers, but little is known about their impact on caregivers of older adults or employers

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# Evidence on an array of interventions to support family caregivers is available

- ❑ The most effective interventions are tailored to caregivers' risks, needs, and preferences.
  - Thus, it is clear that caregiver assessment is essential
  - Education and skills training can improve caregiver confidence and ability to manage daily care challenges
  - Counseling, self-care, relaxation training, and respite programs can improve both the caregiver's and care recipient's quality of life.
- ❑ Some research suggests that personal counseling and care management may delay older adults' institutionalization and reduce re-hospitalization
- ❑ Numerous barriers limit caregivers' access to such services
- ❑ Additional research is needed to determine the effectiveness of interventions in diverse groups of caregivers

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# Systemic barriers often prevent family caregivers from effectively engaging in the care of older adults

- ❑ Family caregivers interact with a wide range of professionals (from physicians to home health aides) and care organizations (home health agencies, hospitals, pharmacies, nursing homes, and others)
- ❑ Yet they are often excluded from older adults' treatment decisions and care planning
  - Even though care providers assume the caregiver is able and willing to perform essential tasks
- ❑ Too often, care providers
  - Do not identify or assess the family caregiver
  - Do not seek critical health information about the older adult from the caregiver
- ❑ Other barriers include payment rules that discourage provider interactions with family caregivers; misinterpretation of HIPAA privacy rules; lack of training to work effectively with family caregivers

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# Recommendations

The focus of the nation's health care reforms should change from person-centered care to *person- and family-centered care*.

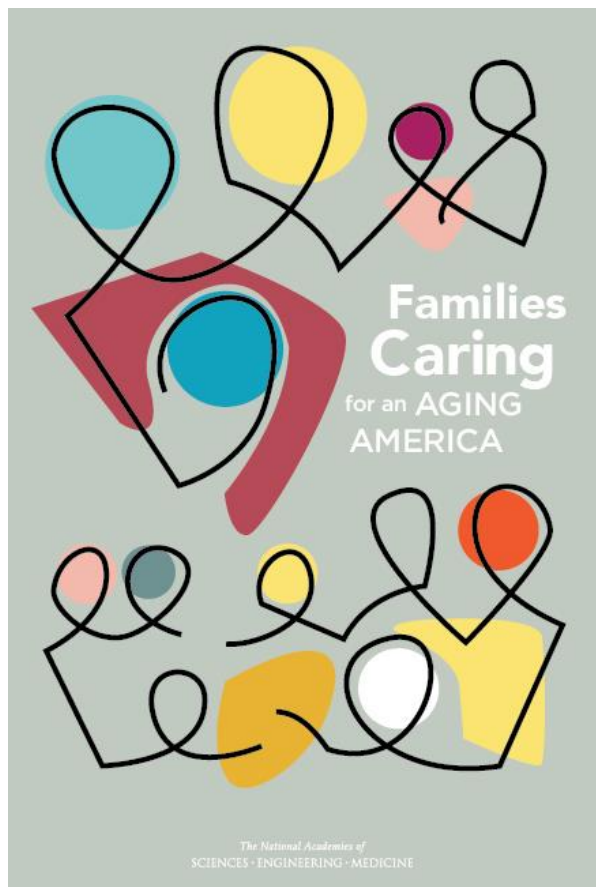
- ❑ The Secretary of HHS, working with the Secretaries of Labor and Veterans Affairs, and others should create and implement a National Family Caregiver Strategy that includes (1)
  - mechanisms to ensure that family caregivers are routinely identified in delivery of services to older adults who rely on help (1a)
  - Medicare and Medicaid payment reform to motivate providers to engage family caregivers effectively (1b)
  - training of health care and LTSS providers to engage with and support caregivers (1c)
  - dissemination and funding for evidence-based caregiver services (1d)
  - evaluation and adoption of federal policies that provide economic support to working caregivers (1e)
  - expanded data collection to improve reporting and analysis on the experience of family caregivers (1f)
  - a multi-agency research program to evaluate caregiver interventions in real-world settings and across diverse conditions and populations (1g)

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# Recommendations cont'd

- ❑ There will be new costs partially offset by saving but requiring rigorous evaluation and transparency
- ❑ States that have not addressed the needs of family caregivers of older adults should learn from the states that provide services and supports to caregivers and implement similar programs (2). For example:
  - 14 states have expanded eligibility for the FMLA
  - 4 states have expanded their Temporary Disability Insurance programs to provide partial wage replacement for family leave (include caregiving of older adults)
- ❑ The Secretaries of HHS, Labor, and Veterans Affairs should work with leaders in health care and LTSS delivery, technology, and philanthropy to establish a public-private innovation fund (3)
  - The fund could leverage private funding to accelerate R&D in assistive technologies, remote monitoring and sensing systems, telehealth applications, and other tools to assist family caregivers
- ❑ All the above actions should explicitly address the diversity of older adults and their family caregivers (4)

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## Questions?

**Download the report for free at:  
[www.nationalacademies.org/caregiving](http://www.nationalacademies.org/caregiving)**

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