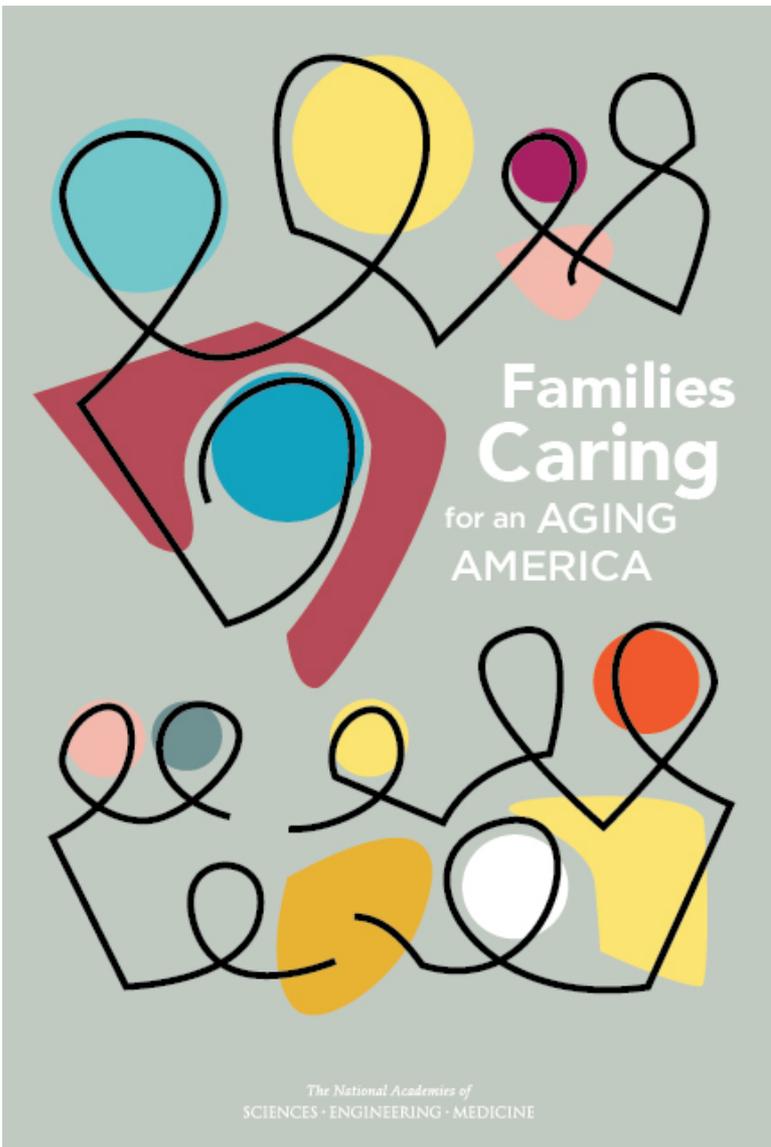


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# *Families Caring for An Aging America*

Richard Schulz, PhD  
Department of Psychiatry, U. of Pittsburgh



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# Family Caregiving for Older Adults

- ❑ 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 caregivers' 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

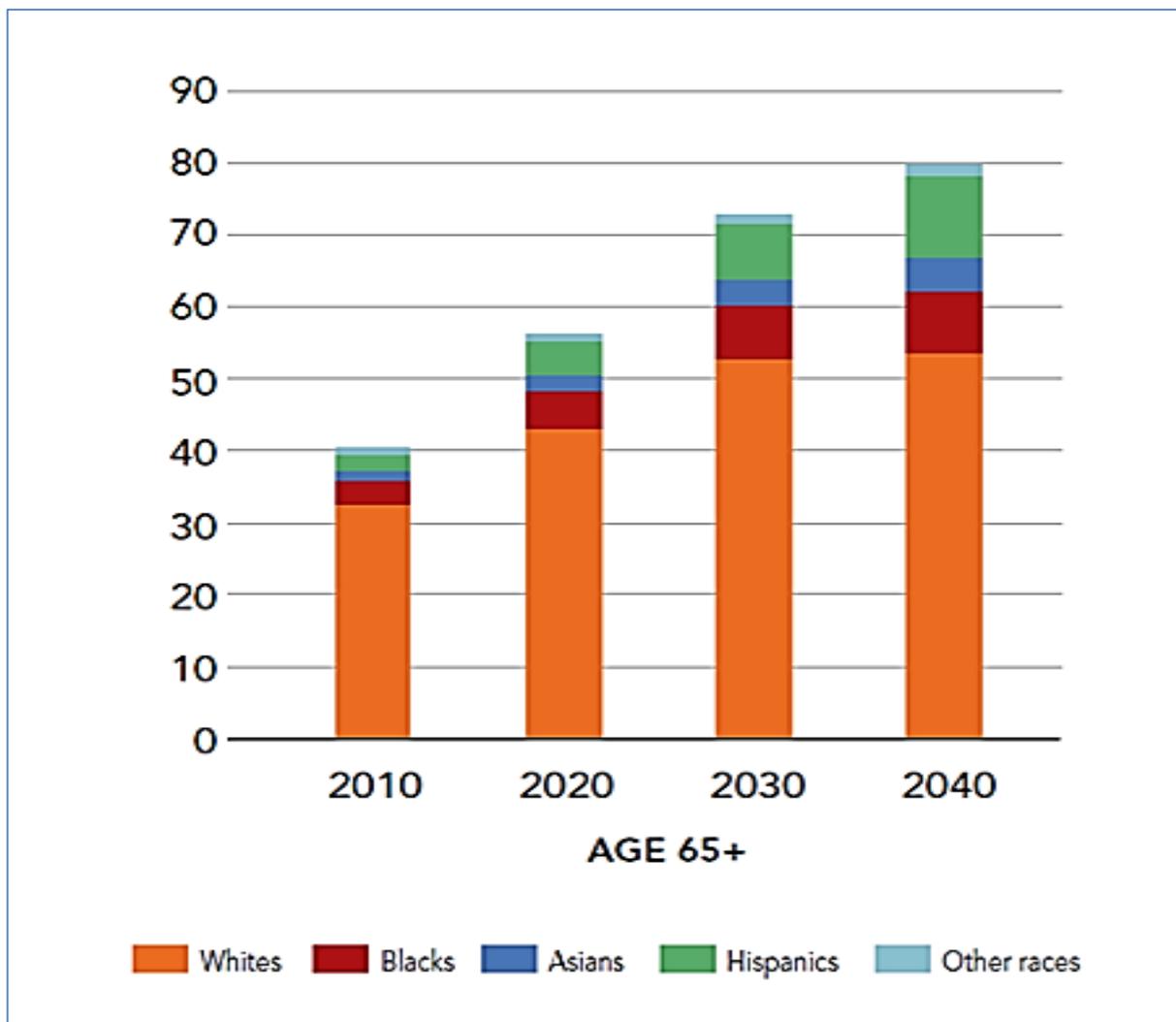
- To assess the prevalence and nature of family caregiving of older adults
- To assess the impact of caregiving on individuals' health, employment, and overall well-being
- To recommend policies to address caregivers' needs and to help minimize the barriers they encounter in acting on behalf of an older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

# Rapidly Rising Numbers of Older Adults and Fewer Family Caregivers to Help Them

- ❑ Historic demographic changes
  - 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+
  - Most likely to have a physical or cognitive impairment
  - Demand for caregivers is growing rapidly
- ❑ 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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# Changing Racial and Ethnic Diversity, U.S. Older Adults, 2010 to 2040 (in millions)



SOURCE: Adapted from Frey, 2014

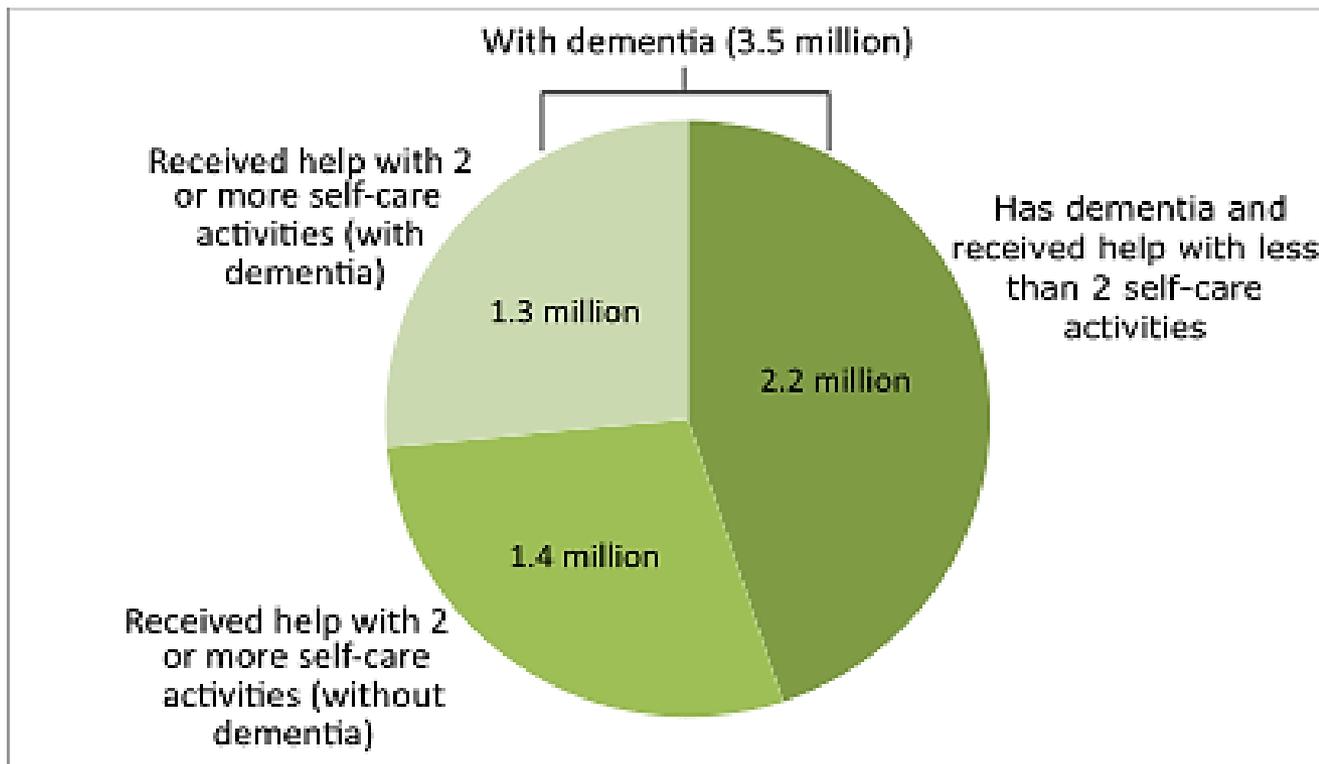
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# Older Adults' Need for Help Varies Widely

- ❑ 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)
- ❑ Care 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

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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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# 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 Can Pose Substantial Financial Risks

- ❑ Many family caregivers of older adults report moderate to high levels of financial strain
- ❑ Family caregivers at the greatest risk of financial harm include those who:
  - are caring for significantly impaired older adults
  - are low-income or have limited financial resources
  - reside with or live far from the care recipient
  - have limited or no access to paid leave (if they are employed)
- ❑ Caregivers may also incur substantial out-of-pocket expenses:
  - medical/medication associated costs
  - assistive devices/home modifications
  - home health aides

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# Family Caregiving and Employment Related Costs

- ❑ More than half of family caregivers are employed part- or full-time
- ❑ Caregivers may lose income, Social Security/ retirement benefits, and career opportunities if they have to modify work hours or leave the workforce
- ❑ **Many employed family caregivers do not have unpaid or paid leave benefits at work or are not eligible for the unpaid protections of the Family and Medical Leave Act (FMLA):**
  - Daughters, sons-in-laws, stepchildren, grandchildren, siblings
  - 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



# Programs and Supports for Caregivers of Older Adults

- ❑ An abundance of evidence on a wide array of interventions and supportive approaches to support family caregivers is available
- ❑ Our approach to the review of the evidence:
  - Defined intervention broadly – therapeutic strategies (e.g., skill building), care delivery models, programs and services
  - Considered interventions for caregivers caring for older adults with a wide range of conditions
  - Considered five categories of outcomes – psychological, physical, social/support service use, economic and positive effects
  - Considered the heterogeneity of the caregiving experience and the caregiving trajectory and how interventions address diversity
  - Considered the role of technology in delivering services/support
  - Considered issues associated with implementation of interventions

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# Framework for Caregiver Interventions



FIGURE 1: *Organizational Framework for Reviewing Family Caregiving Interventions*

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# Programs and Supports for Family Caregivers of Older Adults

- ❑ Evidence indicates that a wide variety of intervention approaches (education and skills training, counseling, self-care and relaxation training, environmental modifications, respite programs, care coordination) can improve caregiver outcomes:
  - caregiver confidence and ability to manage daily care challenges
  - both the caregiver's and care recipient's quality of life
  - may delay older adults' institutionalization and reduce re-hospitalization, shorten hospital stays
- ❑ Effective interventions:
  - incorporate an assessment of caregivers' needs and preferences which are tailored accordingly
  - actively involve the caregiver in learning a skill

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# Programs and Supports for Family Caregivers of Older Adults

- ❑ Most intervention trials have focused on caregivers of older adults with Alzheimer's Disease and on a single caregiver
- ❑ Additional work is needed to identify optimal strategies to disseminate and maintain effective interventions and programs
- ❑ Additional research is needed to determine the effectiveness of interventions in diverse groups of caregivers
- ❑ Technologies (e.g., Internet, mobile apps) are increasingly being used to support family caregivers:
  - Technology-based interventions are feasible, acceptable, and can improve caregiver outcomes
  - Few studies have considered cost issues, issues of diversity
  - Most studies have focused on caregivers of older adults with ADRD

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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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# Some Examples...

- ❑ Deloitte's Paid Family Leave Program
  - ❑ 16 weeks of paid leave per year
  - ❑ Bond with child through birth/adoption; care for spouse parent, child, sibling
- ❑ WELLMED Caregiver SOS program
  - ❑ Caregiver referral integrated into electronic medical record
  - ❑ Embedded caregiver training and support in clinics
- ❑ Molina Healthcare—Promising Practices
  - ❑ Evidence based screening
  - ❑ Caregiver training
  - ❑ Community resource guide
  - ❑ Improved care coordination

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# Washington State Program: Delay use of Medicaid

- Paid family caregivers
- Caregiver Assistance Services
- Training and Education
- Specialized Medical Equipment and Supplies
- Clinical or therapeutic services for caregiver to remain in role

# Defining the Problem: Family Caregivers in Care Delivery

- ❑ Family caregivers interact with varied professionals within and across diverse service delivery settings
  - Provide information about older adults' health and treatments
  - Participate in medical decision-making
  - Support, enact, oversee older adults' care plan
- ❑ The current care delivery orientation is person-focused
  - Provider payment is directed to the insured individual
  - Health professional education is focused on supporting patients
  - Clinical assessments and data infrastructure capture patient-level information
  - Bioethical orientation is toward support of patient autonomy
  - Legal and regulatory emphasis is on data privacy and security, risk management

# Implications of Care Delivery Paradigm

- ❑ Care providers generally do not:
  - Identify older adults who rely on a family caregiver
  - Identify family caregivers who are present in care processes
  - Assess family caregiver knowledge, skill, or capacity to provide assistance in light of their personal circumstances and resources
  - Provide support to family caregivers or initiate appropriate referrals
- ❑ Family caregivers are often implicitly assumed to be available and able to provide care - even as they are marginalized or excluded from care planning
- ❑ Missed opportunities for better preparation and support of caregivers, with consequences for care quality and outcomes of both caregivers and older adults

# Missed Opportunities and Drawbacks

Caregivers who are not adequately prepared or supported experience:

- ❑ Stress and anxiety, fear unintentionally making an error or causing injury
- ❑ Suffer burnout or depression when they are asked to do too much

Older adults also suffer when caregivers are not adequately prepared or supported. Older adults may:

- Be marginalized in their own care, or receive care inconsistent with their preferences
- Experience delayed or unmet service needs
- Be at risk for inappropriate medication use
- Experience neglect or potential abuse
- Receive poor quality or fragmented care
- Incur avoidable service use, such as ED visits or hospitalization

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# Priority Areas for Action

1. Identification, assessment, and support of family caregivers in delivery of care
2. Inclusion of both family and caregiver experiences in quality measurement
3. Support of family caregivers through health information technology
4. Preparation of care professionals to provide person- and family-centered care

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# Recommendations

## A Vision for the Future:

- ❖ No less than a transformation in the policies and practices affecting the role of families in the support and care of older adults
  - ❑ The focus of the nation's health care reforms should evolve from person-centered to *person- and family-centered care*
  - ❑ Support of family caregivers should be recognized as an integral part of the nation's *collective responsibility* for caring for older adults with health and functional needs
  
- ❖ The Committee calls upon the new Administration to take steps to address the health, economic, and social issues facing family caregivers of older Americans

# Recommendations

1. 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:
  - A. Effective mechanisms to ensure that family caregivers are routinely identified and their needs are assessed and supported
  - B. Medicare and Medicaid payment reform to motivate providers to engage family caregivers effectively
  - C. Training of health care and social service providers to recognize, engage, and support family caregivers

# Caregiver Assessment

Who	When	What	Where	Assessor
<p>Primary caregiver responsible for patient care; entered in patient and caregiver medical record</p>	<ul style="list-style-type: none"> <li>• Wellness/follow-up visits for patient/caregiver</li> <li>• Care transitions (admission/discharge from hospitals, emergency rooms/rehab facilities to home)</li> <li>• Chronic care transitions/ change in patient status</li> <li>• Regular follow-up monitoring</li> </ul>	<ul style="list-style-type: none"> <li>• Health/ functional and emotional status of caregiver</li> <li>• Knowledge and skills for required care tasks</li> <li>• Willingness to carry out required tasks</li> <li>• Financial and human support resources available to caregiver</li> <li>• Training and support needed</li> </ul>	<ul style="list-style-type: none"> <li>• Physician offices</li> <li>• Receiving/discharge facility</li> <li>• Caregiver/patient home</li> <li>• Senior Centers</li> </ul>	<ul style="list-style-type: none"> <li>• Primary care provider</li> <li>• Discharge planners</li> <li>• In-home assessors</li> <li>• Caregiver specialists</li> </ul>

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# Recommendations

National Family Caregiver Strategy that includes:

- D. Dissemination and funding for evidence-based caregiver services
- E. Evaluation and adoption of federal policies that provide economic support to working caregivers
- F. Expanded data collection to improve reporting and analysis on the experience of family caregivers
- G. A multi-agency research program to evaluate caregiver interventions in “real-world” settings and across diverse conditions and populations.

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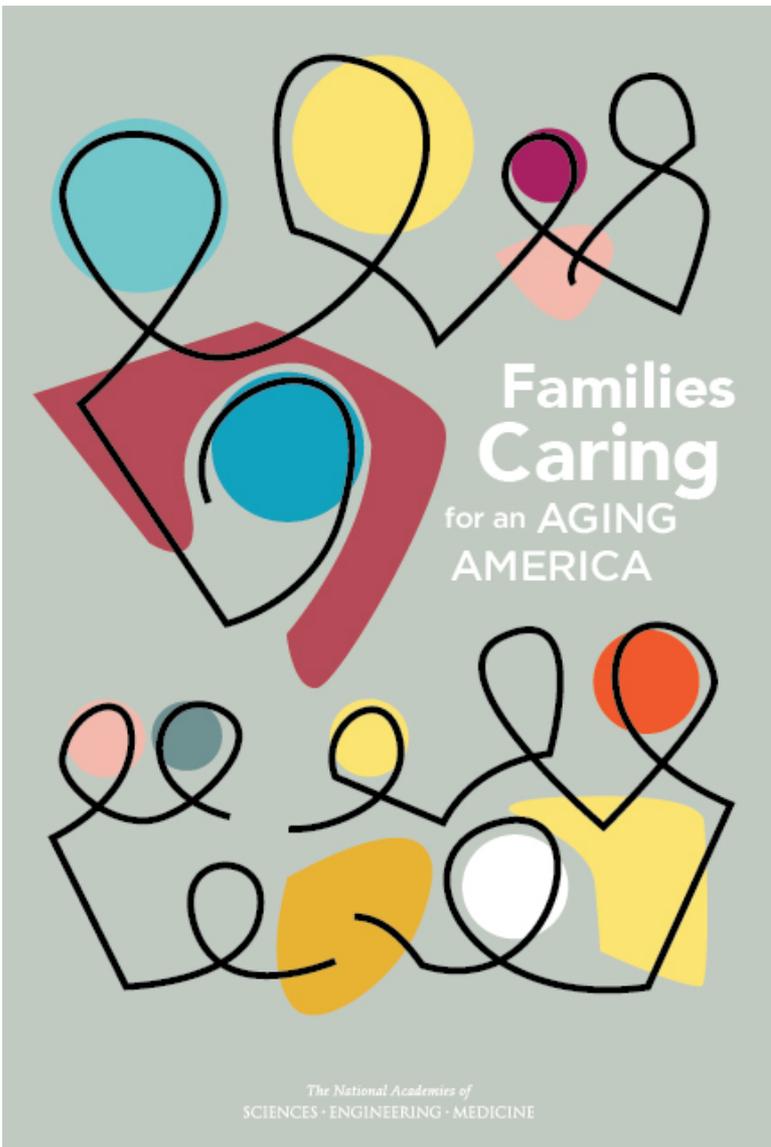
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# Recommendations

2. 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
3. The Secretaries of HHS, Labor, and Veterans Affairs should work with leaders in health care and LTSS, technology, and philanthropy to establish a public-private innovation fund to accelerate the pace of change
4. All the above actions should explicitly address the diversity of older adults and their family caregivers

# Some Hopeful Signs...

- RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act
- Credit for Caring Act—tax credit up to \$3000 for financially helping relative
- Caregiver Advise, Record, Enable (CARE) Act - discharge planning, Adopted in 30 states



## Questions?

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