

# **Supporting Family Caregivers**

Reforming States Group  
Pre-Conference Meeting  
November 29, 2017

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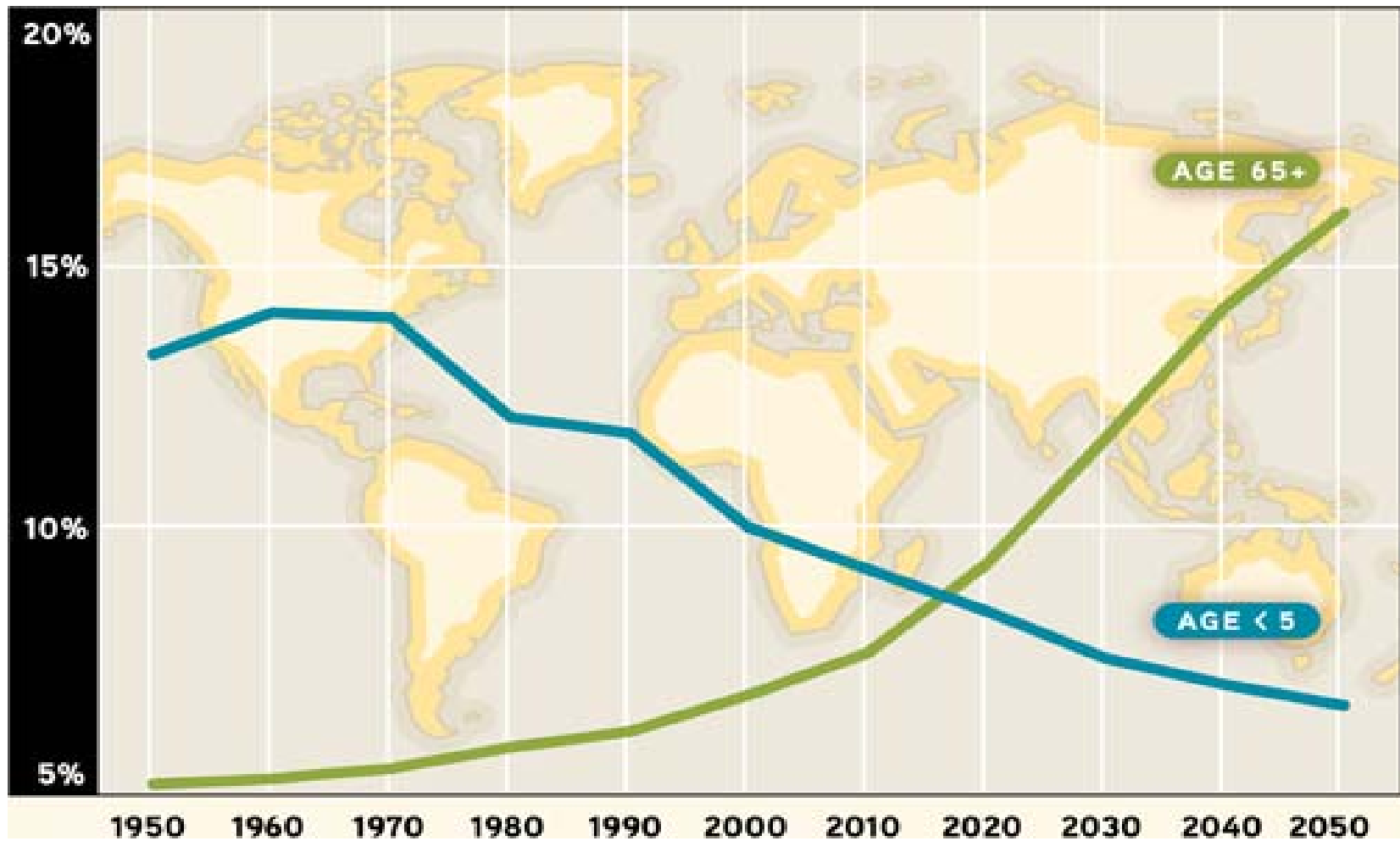
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# Overview

1. Family caregiving: an important issue for public policy in an Aging America
2. Family caregiving: what would meaningful support look like?
3. Family caregiving and state policy:  
What states can do
4. Discussion



# Population Aging: a Global Phenomenon



Source: United Nations Department of Economic and Social Affairs, Population Division.

World Population Prospects. The 2004 Revision. New York : United Nations, 2005.



## **Who Will Care For You?**

Understanding the facts about elder care  
and assisted living will help you and your family  
be prepared and protected

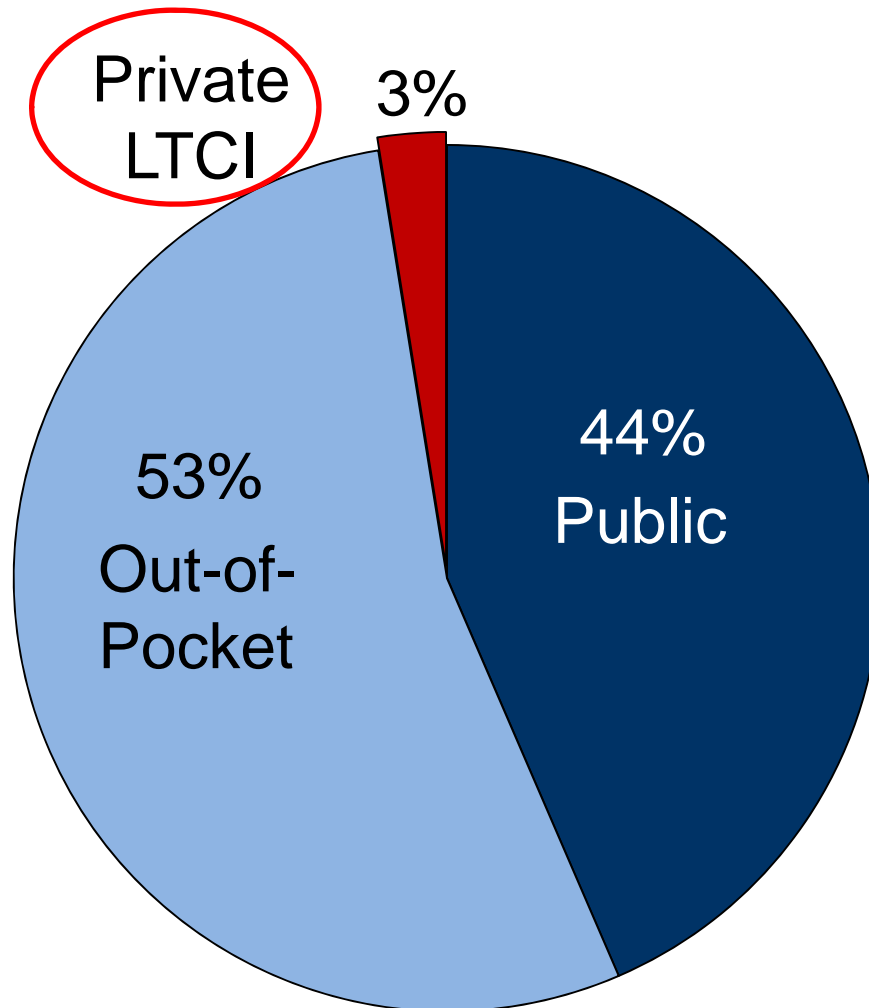


## **October 2017 Issue**

### Elder Care & Assisted Living: Who Will Care for You?

- Long-Term-Care Insurance Gets a Makeover
- 11 Ways to Pay for Assisted Living
- What Assisted Living Costs State by State

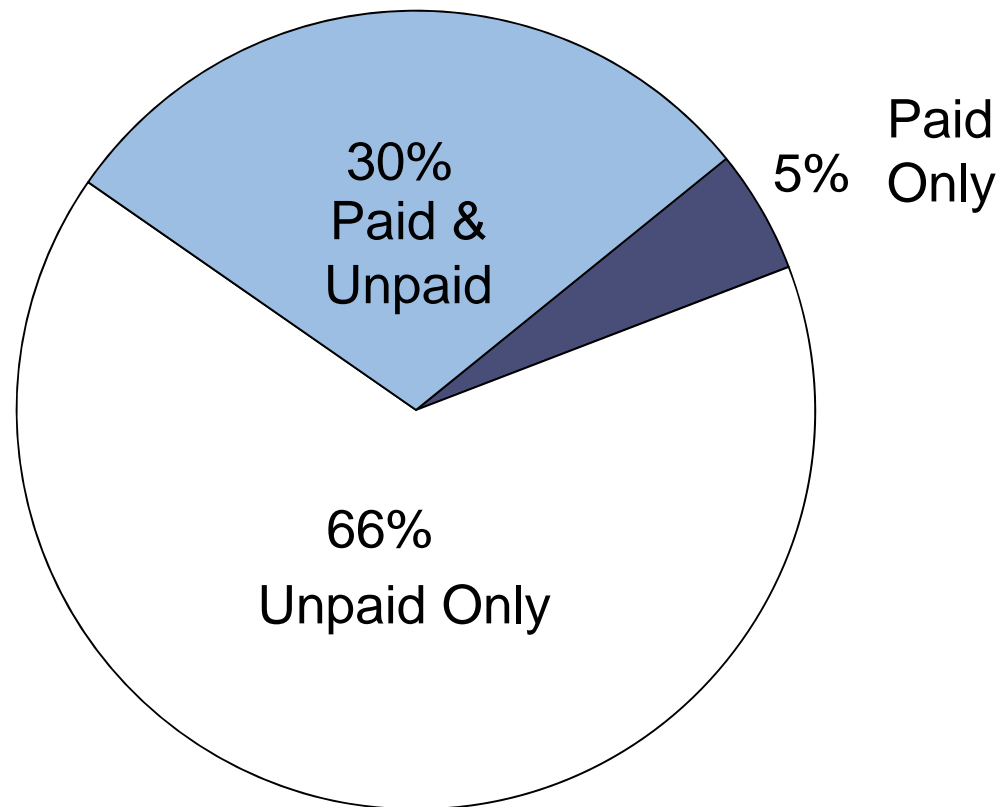
# >50% of Long-Term Services and Supports is Financed Out of Pocket



Lifetime LTSS Expenditures: \$266,000

Source: Favreault & Day, 2015 ASPE Research Brief.

## Most LTSS for Older Adults With Disabilities Is Provided by Family and Unpaid Caregivers



Data Source: 2011 National Health and Aging Trends Study.

**Unpaid. Unappreciated. Untrained.  
Undercounted. Exhausted. But vital.**

*“America’s stealth weapon against chronic illness is a 46-year-old woman with a family, a high-school degree, a full-time job and a household income of \$35,000. She has no particular training in health care. And, to tell you the truth, sometimes she doesn’t feel that great herself...”*

-- AMA Medical News, 2001

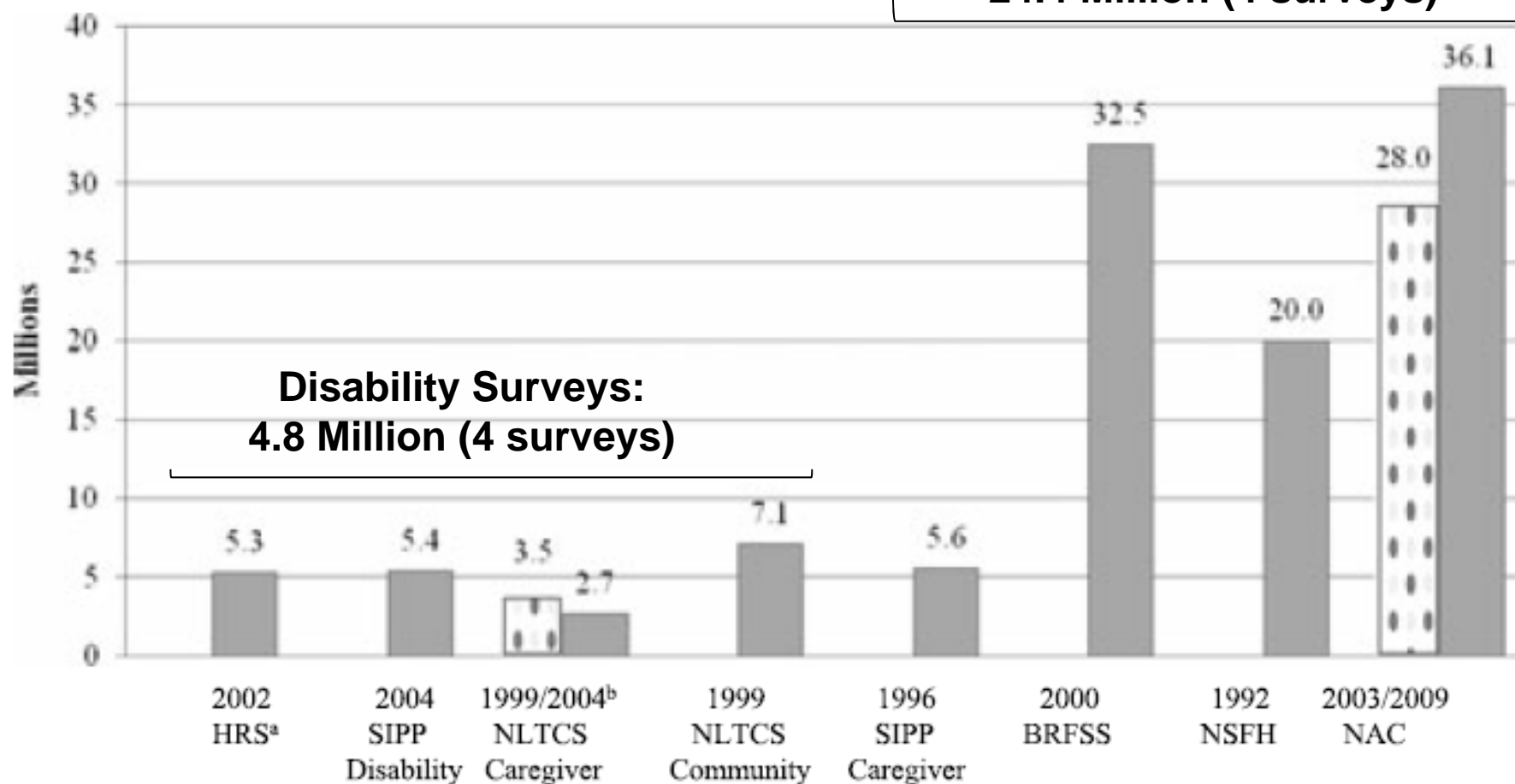


# Cross-Survey Differences in National Estimates of Numbers of Caregivers of Disabled Older Adults

ERIN R. GIOVANNETTI and JENNIFER L. WOLFF

*Johns Hopkins University*

**Caregiver Self-identification Surveys**  
**24.4 Million (4 surveys)**

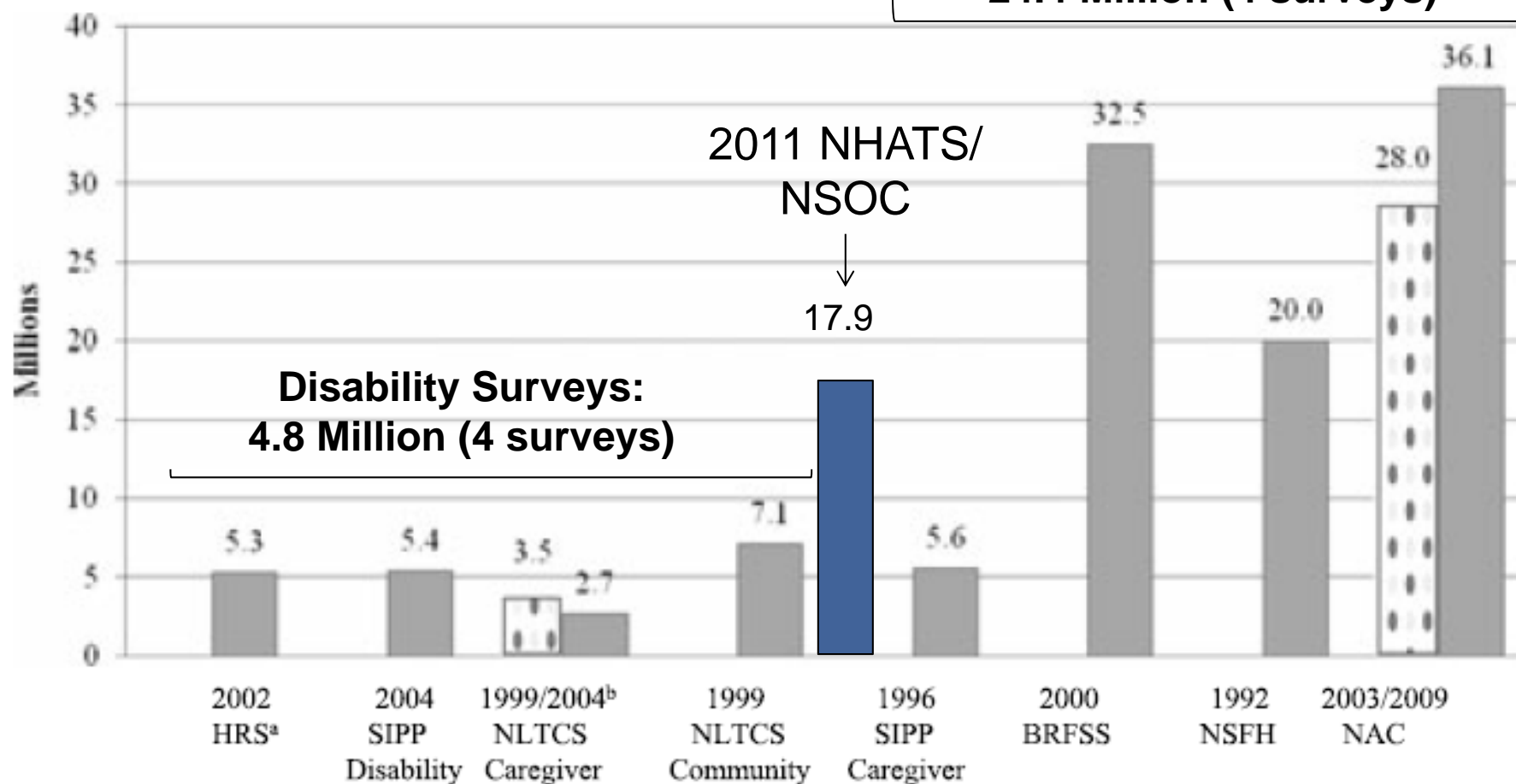


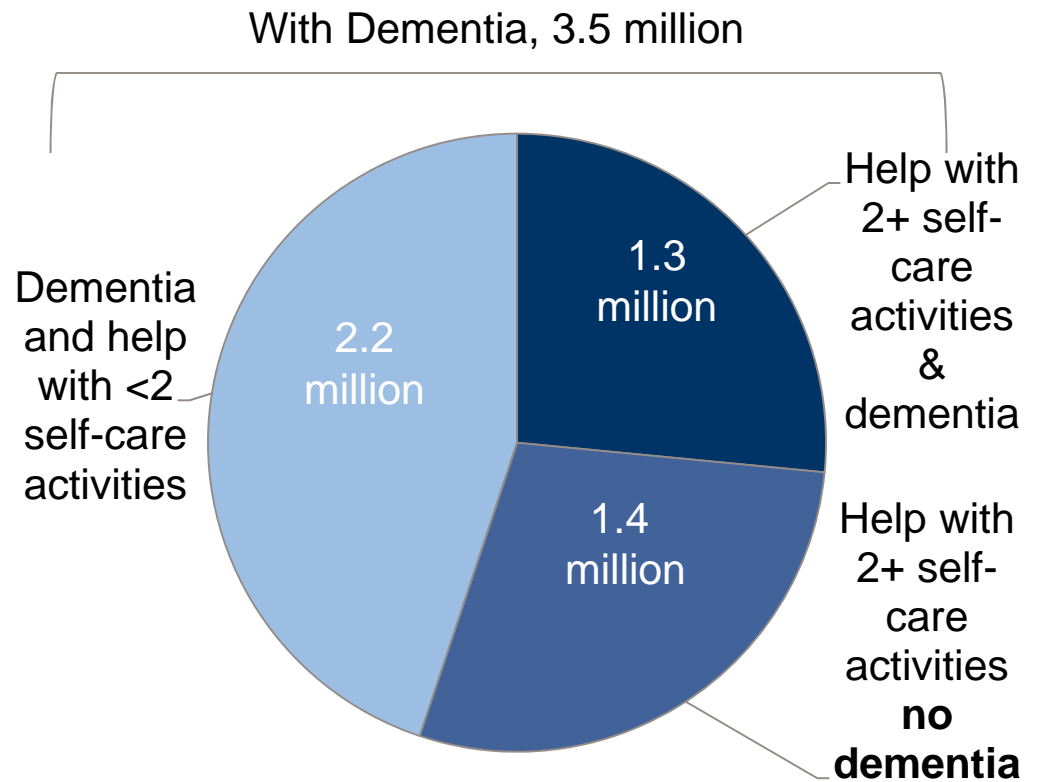
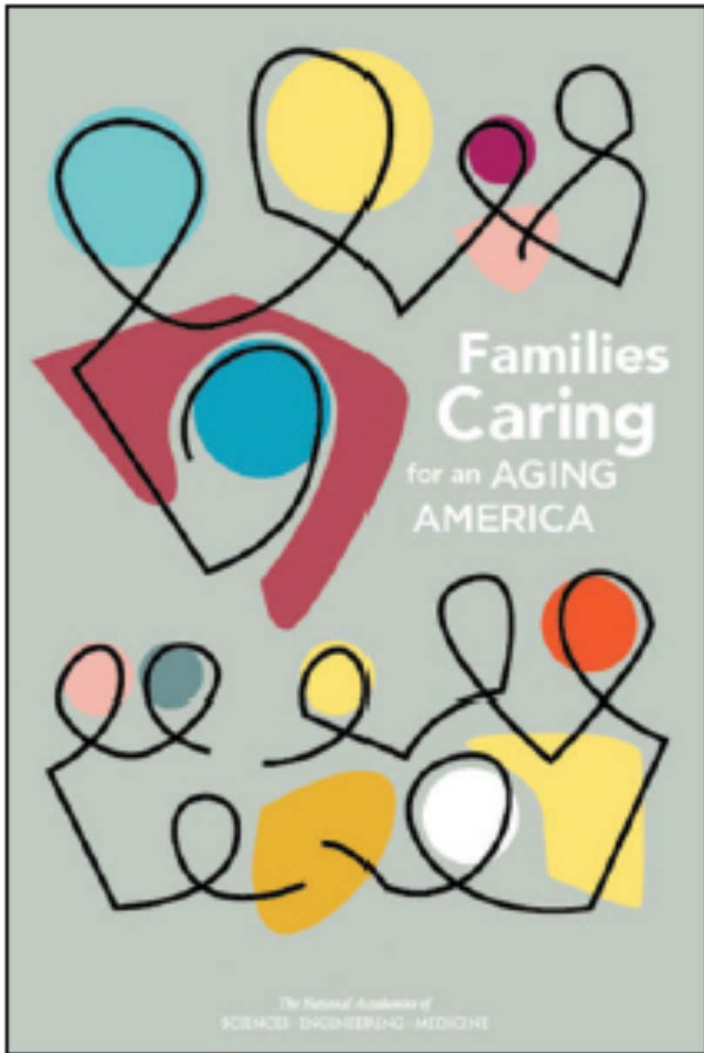
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**Caregiver Self-identification Surveys**  
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## 8.5 million caregivers provide help to 4.9 million high-need older adults (persons with dementia and/or 2 or more self-care needs), 2011

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.

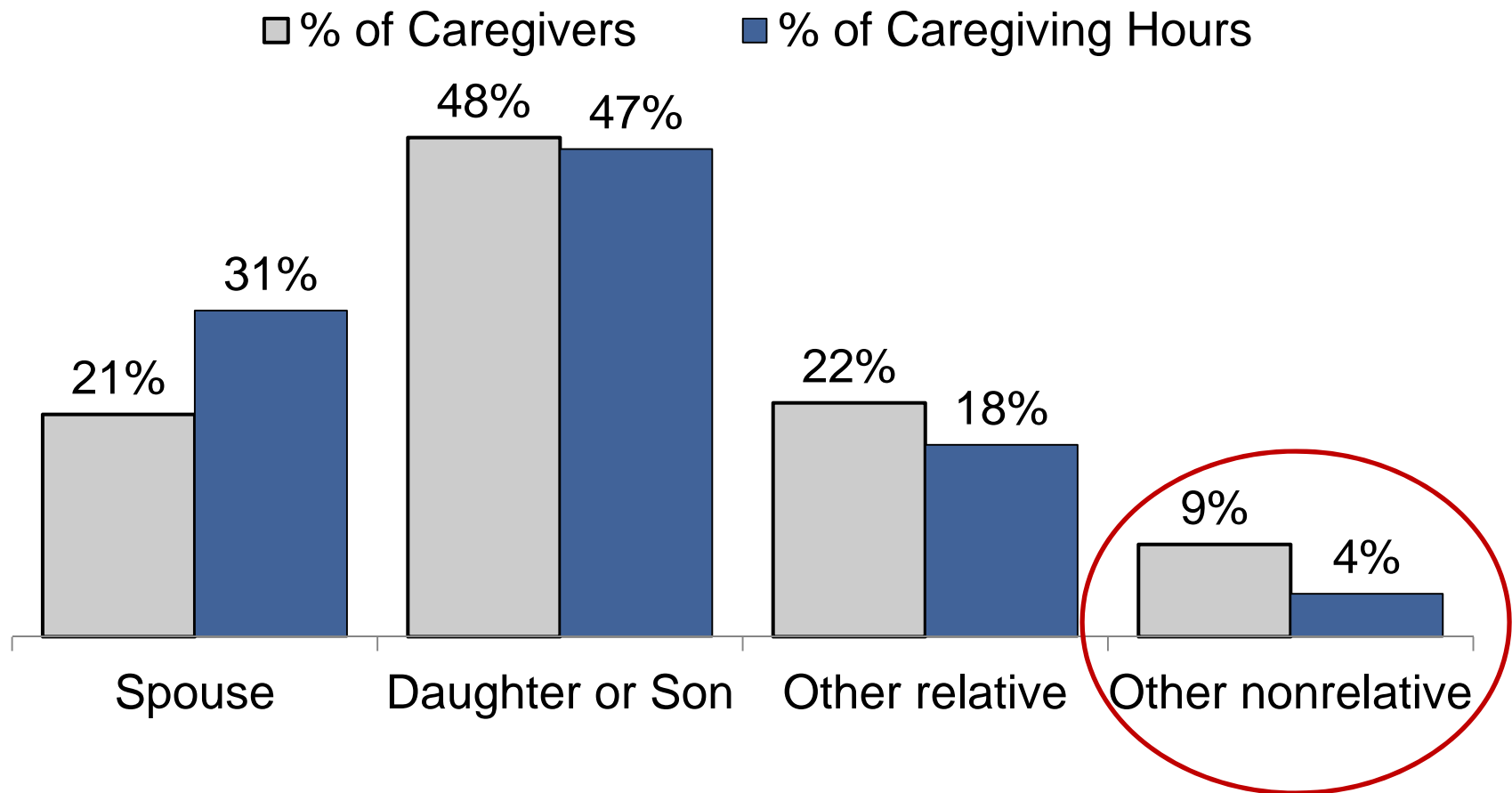
SOURCE: Data from the 2011 NHATS

# A Snapshot: Family Caregivers of Older Adults

- Reflect the diversity of the US: they come from every age, gender, race/ethnicity, and socioeconomic status
- 60% female; 40% male
- More than half (50.3%) work at a paying job
- Average hours of care/week: 19.5 hours
- 60% provide care for 4+ years
- More than 1 in 3 (34%) care for someone with dementia
- 17% of older adults with health and functional needs reside in rural areas

*Source: 2015, National Health and Aging Trends Study & National Study of Caregivers*

# Family Members Comprise the Majority of Caregivers and Contribute Majority of Caregiving Hours



Source: April 2014 ASPE Report, Analysis of 2011 National Study of Caregivers.  
BC Spillman, JL Wolff, VA Freedman, JD Kasper.

## Discussion

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- Do these national statistics resonate?
- What does your state look like?
- What is the prevalence of dementia in your state?
- Is there anything surprising here?

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## The Effects of Caregiving are Variable

- 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

Source: National Academies of Sciences, Engineering and Medicine. 2016. *Families Caring for an Aging America*. Washington, DC: The National Academies Press.

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## Family Caregiving Can Pose Financial Risks

- Some 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
  - have limited or no access to paid leave (if they are employed)
- Some caregivers may incur substantial-out-of-pocket expenses:
  - medical/medication associated costs
  - assistive devices/home modifications
  - home health aides

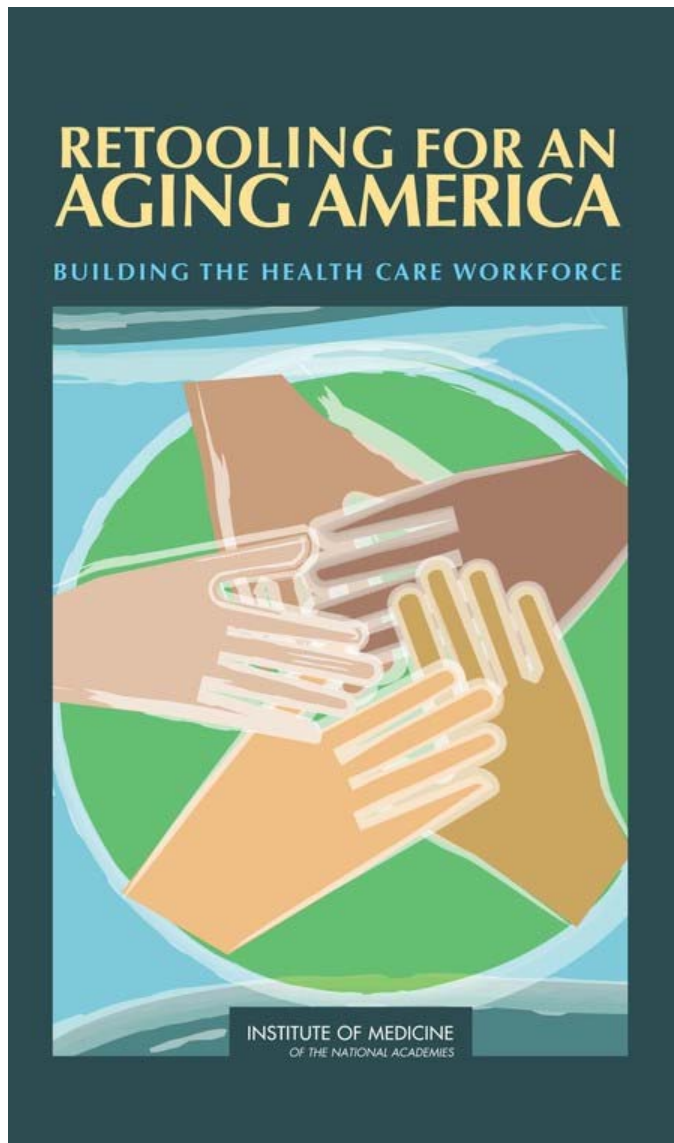
*Source:* National Academies of Sciences, Engineering and Medicine. 2016. *Families Caring for an Aging America*. Washington, DC: The National Academies Press.



# Family Caregiving and Employment

- About 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, grandchildren, siblings
  - Employees of small firms

*Source:* National Academies of Sciences, Engineering and Medicine. 2016. *Families Caring for an Aging America*. Washington, DC: National Academies Press.



<b>Health-Related Responsibilities Assumed by Family Caregivers</b>	
<b>Role</b>	<b>Function</b>
Attendant	Provide personal care
Administrator	Manage household
Health Provider	Deliver medical care
Companion	Provide emotional support
Driver	Facilitate transportation
Advocate	Request services
Navigator	Coordinate care across providers and care settings
Coach	Encourage patient self care activities
Technical Interpreter	Facilitate patient understanding
Patient Extender	Facilitate provider understanding

From: Wolff J. Supporting and sustaining the family caregiver workforce for older Americans: Commissioned Paper. 2007:35. Located at: Background Paper for IOM Report: Retooling for an Aging America.

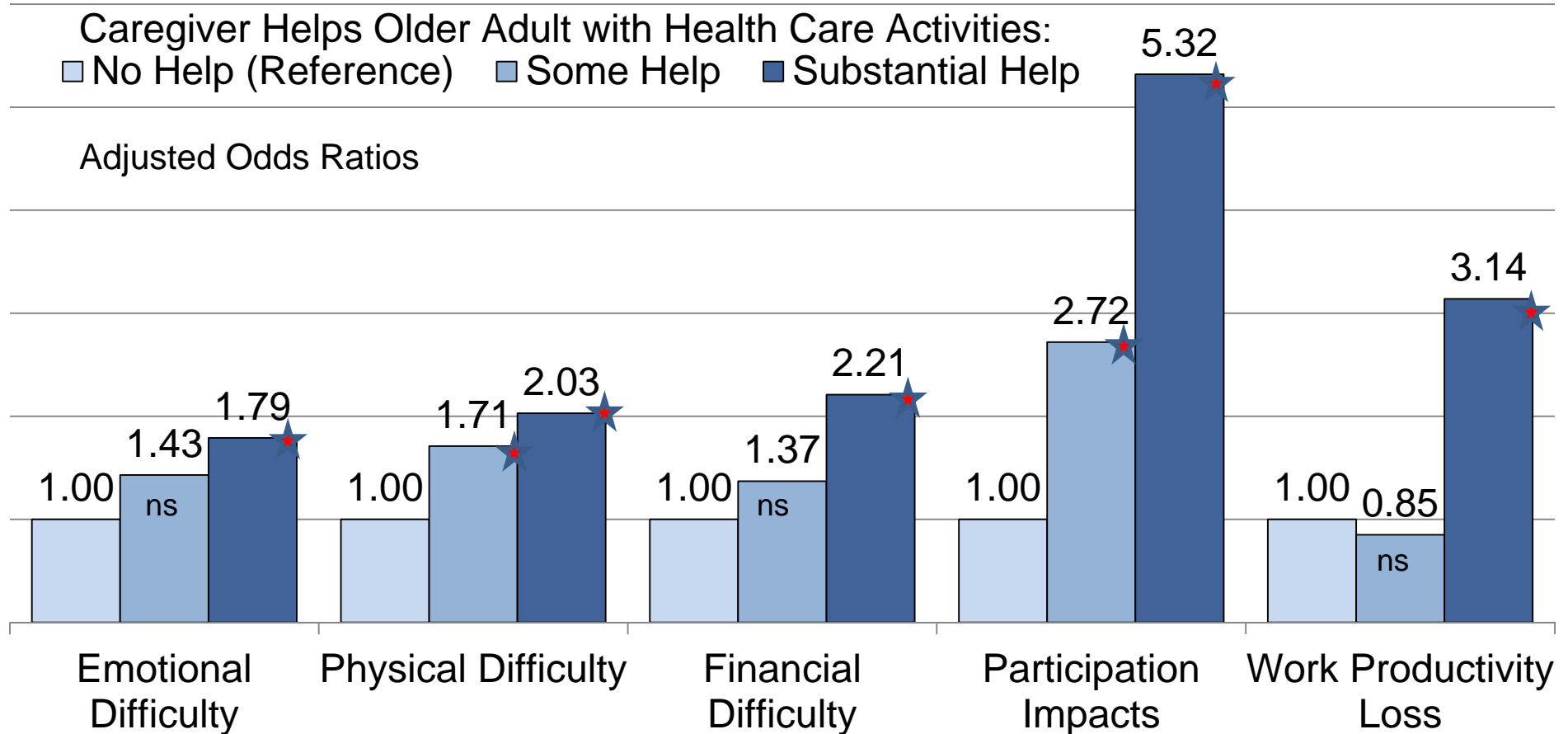
# Challenges to Structural Support of Family Caregivers in Care Delivery

1. Misaligned reimbursement – lack of compensation for clinician time and effort to educate, counsel, or support involved family
2. Prevailing orientation toward patient autonomy and privacy
3. Patient-oriented information systems – lack of structured fields to document information about involved family members/friends

# JAMA Internal Medicine

## A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities

Jennifer L. Wolff, PhD; Brenda C. Spillman, PhD; Vicki A. Freedman, PhD; Judith D. Kasper, PhD



★ Statistically significant in models that adjust for caregiver age, sex, educational attainment, self-rated health, child <18 years in household, work responsibilities, relationship to older adult.

Source: 2011 National Health and Aging Trends Study and National Study of Caregivers.

**A descriptive qualitative study of the roles and behaviors of family companions in primary care visits among older adults with cognitive impairment**

*Vick JB, Amjad H, Smith KC, Boyd CM, Gitlin LN, Roth DL, Roter DL, Wolff JL*

*“If somebody wants to be alone with him, if a doctor wants some alone time with P, that’s fine. But the fact of the matter is he’s not going to remember what was talked about... **Clinicians get angry with me, and they’re like “Let him speak,” as if this is picnic for me, which it is not...** And as a matter of fact, it’s very disturbing to know that he can’t remember that he had a stent put in his heart [last month]...”*

- 60 yo spouse of person with MCI (MMSE 26)

## Discussion

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- Is there anything surprising here?
- How does this information correspond with your own experiences?

**What Would Meaningful Support for  
Family Caregivers Look Like?**

# What Do Caregivers Need?

- Information, Knowledge, Skills, Resources
- Respite, to have a break!
- Reinforcement, help & support from others to reduce physical and emotional strain
- Coping skills, counseling, psychoeducation, problem solving skills
- Financial support, to offset work impacts, out-of-pocket spending
- Flexibility in the workplace



# What Would Meaningful Support for Family Caregivers Look Like?

- Acknowledging the person and family at center of the care team
  - Concept of *person- and family-centered care*
- Advancing more “family friendly” workplaces
- Accessing practical and affordable technologies to improve quality of life for older people and families
- Promoting continuity of care across settings
  - with family caregivers identified in electronic health records
  - and LTSS integrated with health care delivery
- Scaling up accessible, affordable evidence-based support services to help families where they live
  - Such as education and skills training, counseling, respite care
- Developing a larger and higher quality paid direct care workforce to supplement family care

# Caregiver Assessment: The Foundation of Tailored Support

Caregiver assessment: a systematic process of gathering information that describes a caregiving situation that identifies the particular problems, needs, resources, and strengths of the family caregiver. It approaches issues from the caregiver's perspective and culture, focuses on what assistance the caregiver may need and the outcomes the family member wants for support, and seeks to maintain the caregiver's own health and well-being.

## Domains of an Assessment

1. Context: circumstances of caregiver and caregiving situation
2. Perception and reaction to health and functioning of recipient
3. Values and preferences - for everyday living and care provision
4. Health and well-being
5. Consequences of caregiving for caregiver (e.g., stresses, rewards)
6. Care provision requirements, skills, abilities, knowledge
7. Resources to support the caregiver

From Family Caregiver Alliance Consensus Conference (2006)

See [www.caregiver.org](http://www.caregiver.org) for consensus conference report and inventory of instruments.

# **Federal policies**

# What Federal Supports Exist?

- Administration for Community Living (FY2017 \$2.1 billion)
  - National Family Caregiver Support Program (\$151 million)
  - Alzheimer’s Disease Supportive Services (\$15.3 million)
  - Lifespan Respite Care (\$5 million)
- Department of Veterans Affairs (FY2017 \$521 million)
  - Comprehensive Caregiver Program –stipend, health insurance, & services to caregivers of veterans from post-9/11 era who assist with personal care
  - Caregiver Support Line for information & referrals
- New Medicare billing codes (e.g., transitional care management, chronic care management services, advance care planning, health risk assessment) (2013 – 2017)
- Medicaid rule on HCBS settings recognizes importance of assessing needs of family caregivers when care plan depends on them; 1915(i) HCBS state plan option only (2014)

# Federal Initiatives and Proposed Legislation

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- **Assisting Caregivers Today (ACT) Caucus:**
  - Launched March 2015, Bi-Cameral and Bi-Partisan
  - Chaired by Senators Capito (R-WV) and Bennet (D-CO), and Reps. Black (R-TN) and Lujan Grisham (D-NM)
- **Recognize, Assist, Include, Support and Engage Family Caregivers Act (S. 1028)**
  - Bi-Partisan Bill introduced by Senators Collins (R-ME) and Baldwin (D-WI)
  - Requires development, maintenance and updating of an integrated national strategy to recognize and support family caregivers
  - Passed the U.S. Senate by unanimous consent (9/26/17); Introduced 9/13/17 in the House (H.R. 3759) by Reps. Harper (R-MS), Castor (D-FL), Lujan Grisham (D-NM) and Stefanik (R-NY)
- **Credit for Caring Act**
  - Introduced by Reps. Reed (R-NY) and Sanchez (D-CA) in the House (H.R. 2505) and Senators Ernst (R-IA) and Bennet (D-CO) in the Senate (S. 1151).
  - Bill would create a new, non-refundable family caregiver tax credit of up to \$3,000 to help address the financial burdens of caregiving.

# **State policies**

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# State Policies for Family Caregivers

## States with Alzheimer's Plans

- Nearly every state

## States with Family Caregiver Plans

- AL, CA, DE, HI, ID, IN, KY, LA, MD, MS, ND, NE, NJ, NM, SC, VA

## States with Uniform Adult Guardianship Certificates

- Every state except WI, MI, KS, TX, FL



## **Policy Options:**

### Financial

- Caregiver Tax Credits

### Employment

- Employment Anti-Discrimination
- Financial Assistance to Employed Caregivers
- Paid Family Leave and/or Sick Days

### Supports and Services

- Increase Appropriations for Caregiver Support
- Funding for Research / Innovation

### Care Delivery

- CARE Act
- Expansion of telehealth and/or wireless or Internet access for underserved or rural communities
- Change Nurse Delegation Rules to Allow for Home Health to Perform Medical Tasks



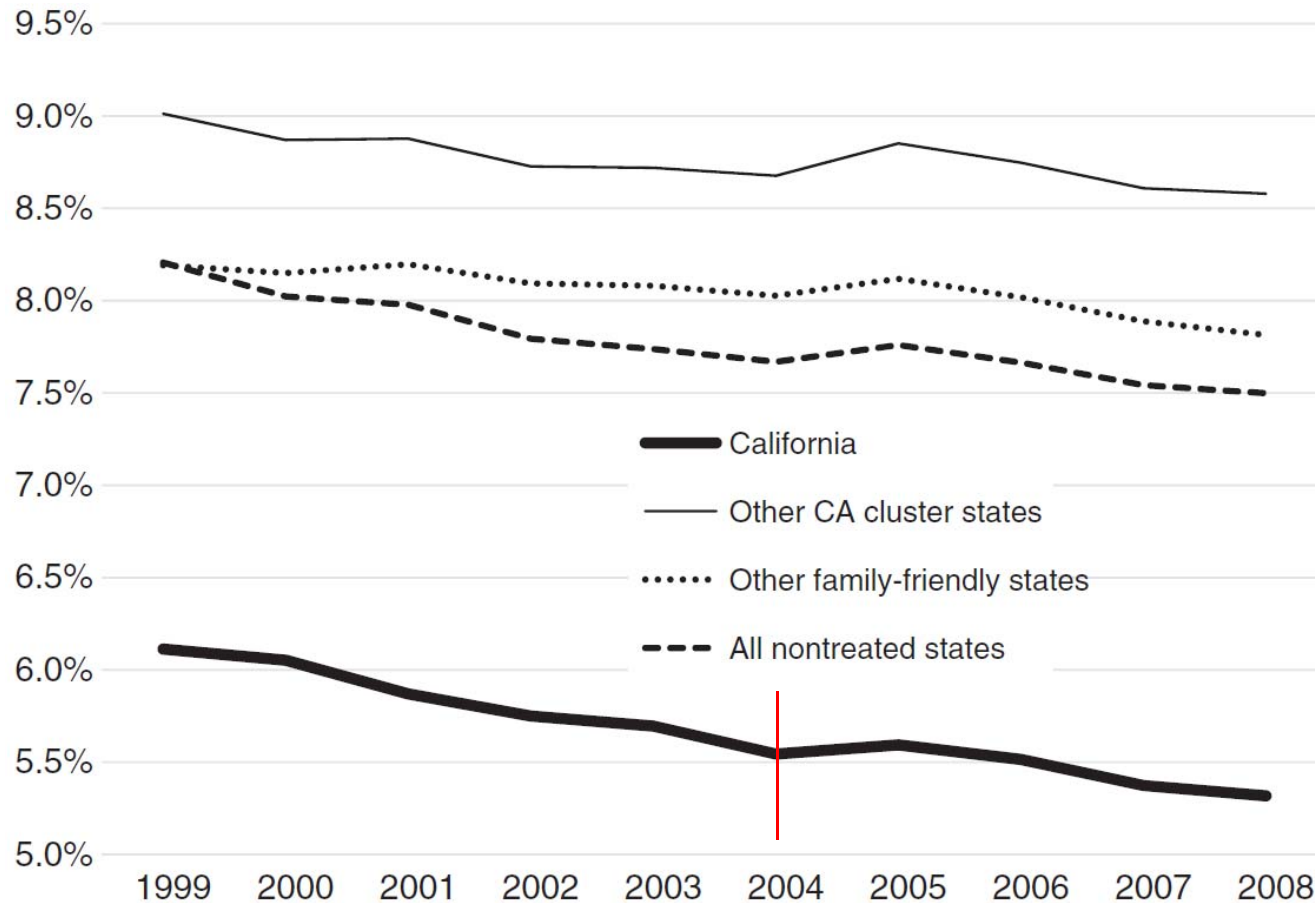
# Supports for Working Caregivers

- Family Medical Leave Act of 1993 ([www.dol.gov/whd/fmla](http://www.dol.gov/whd/fmla))
  - Protects job for up to 12 weeks, unpaid leave
  - Estimated 40% of US workers excluded
- Paid Family Medical Leave
  - 5 states (CA, NJ, NY, RI, WA) and Washington DC
  - Partial pay replacement 4-12 weeks, Funded through insurance model with worker payroll tax
- Paid Time Off – sick leave, personal, or vacation time
  - Typically 8-14 days annually
  - Estimated 40% US workers excluded
- Flexible Schedules, Workplace Supports (counseling, assessment and referral, case manager)

# Does Paid Family Leave Reduce Nursing Home Use? The California Experience

*Kanika Arora  
Douglas A. Wolf*

Journal of Policy Analysis and Management, Vol. 00, No. 0, 1–25 (2017)

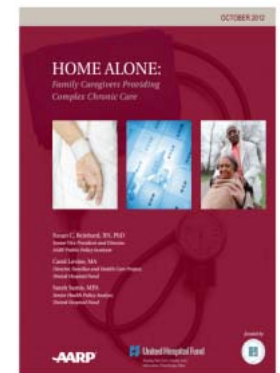


*Notes:* “Other CA cluster” states are DE, MA, MD, ME, MN, ND, NH, NJ, NM, OH, PA, RI, VA, VT, WA, and WI.

“Other family-friendly states” are CT, DC, HI, ME, MN, ND, NJ, NV, NY, OR, RI, TN, VT, WA, and WI.

# Translating Research Into Policy: The CARE Act

- AARP developed model legislation based on the *Home Alone* findings- the **C**aregiver, **A**dvice, **R**ecord and **E**nable (CARE Act)
- Under the CARE Act:
  - Hospitals must identify a family caregiver for inpatient admissions and record the family caregiver in the medical record
  - Hospitals must notify the family caregiver of discharge plans for the person in the hospital
  - Family caregivers must be offered training on medical/nursing tasks they may be asked to perform at home.
- Law in 39 states and territories — and counting!

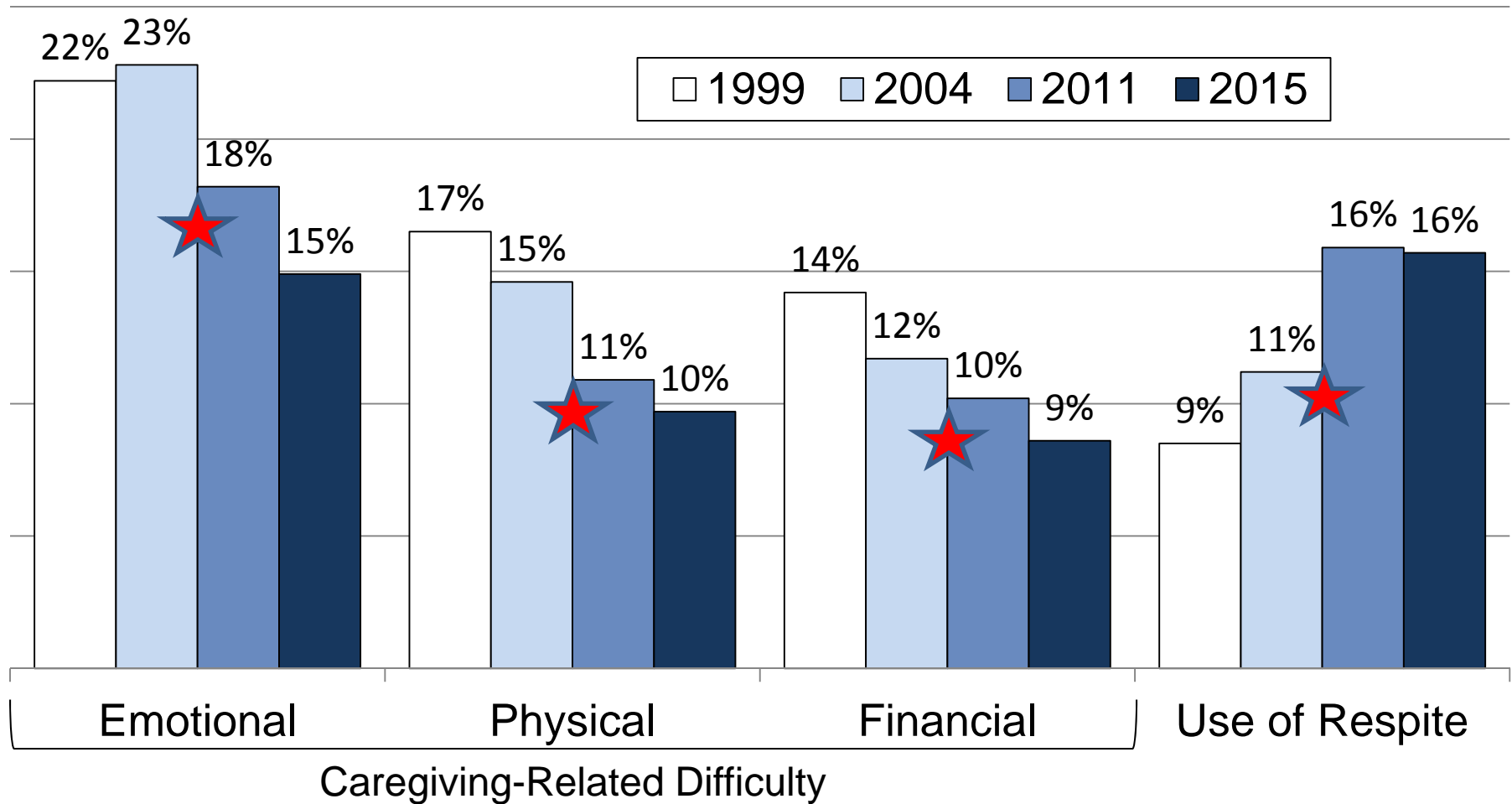


## States Leading the Way: Selected Examples

- **CA** enacts the nation's first paid family leave program (2002)
  - Lifts rate of wage replacement from 55% to 70% for low-income workers (2017)
- **RI's** Family Caregiver Support Act (2013)
  - Requires a caregiver assessment if the plan of care for the Medicaid beneficiary involves a family member
- **TN's** TennCare CHOICES Program
  - Requires managed care orgs. to conduct caregiver assessments (2015), and ensure that identified family members have the care coordinator's contact info (2016)
- **WA State's** 1115 Waiver, Medicaid Transformation Project (2017)
  - Creates a “next generation” system focused on outcomes that support families in caring for older adults at home with LTSS needs
  - Offers services to assist unpaid caregivers in getting necessary supports to continue to provide care and to focus on their own health and well-being
- **HI's** Kupuna Caregivers Act (2017)
  - Offers financial assistance (up to \$70/day in vouchers) to FT employed family caregivers of older adults to help pay for care that they would otherwise do themselves, including care management, home-delivered meals, adult day services, and transportation.
  - Legislature allocated \$600,000 in start-up funds; must be renewed in 2018.

# **Assessing Policy Change: The Value of Evidence**

# 1999-2016: Fewer Caregivers with Substantial Caregiving-Related Difficulty, More Using Respite



★ Statistically significant difference, 1999, 2004, and 2011 vs. 2015

*JL Wolff, J Mulcahy, J Huang, DL Roth, K Covinsky, JD Kasper, The Gerontologist, 2017.*

1999 & 2004 National Long-Term Care Survey & its Linked Informal Caregiver Surveys and the 2011 & 2015 National Health & Aging Trends Survey & Linked National Study of Caregivers