
What States Need to Know and What They Can Do to Support Family Caregivers

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**Public Policy
Institute**

Four Main Points

- Serious illness and chronic disability affect the family as well as the individual.
- Family caregiving today is more complicated, costly, stressful, and demanding than at any time in human history.
- The U.S. is facing an unprecedented care gap.
- It's time to treat family caregiving with a new urgency and make it a federal, state, and local priority.

Family Caregiver ***Broad Definition***

- Any relative, partner, friend or neighbor who has a significant personal relationship with, and who provides a broad range of assistance for, an older person or an adult with a chronic, disabling, or serious health condition.

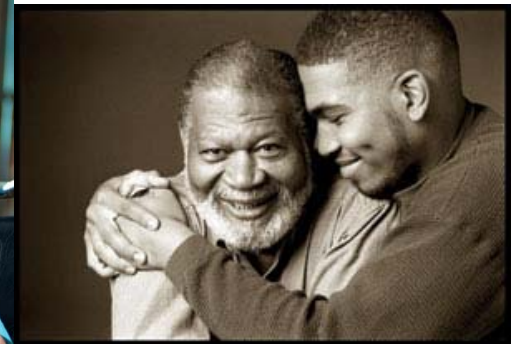


What's Different about Family Caregiving Now than in the Past?

Family Caregiving in the “Old Days”



The “New Normal”



A New Reality: Changing Family Structures

- Share of U.S. adults **never marrying** is at an historic high
 - 1 in 5 (20%) adults age 25+ has never married—up from 9% in 1960
- **Greater childlessness**
 - Nearly 20% of women are childless today; 10% in 1970
 - % of frail older adults without any surviving children is projected to increase from 14% (2010) to 21% (2040)
- **More divorce** among people age 50+
 - Divorce rate of 50+ pop. roughly doubling since the 1990s

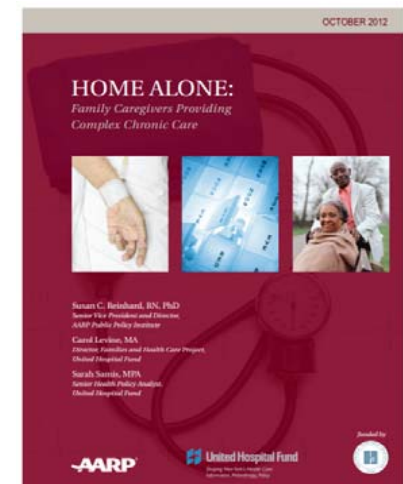
- Extended duration of caregiving as people live longer with multiple chronic conditions
- More geographic dispersion
- Greater complexity of family caregiving role
 - Both “care coordinators” and “service providers”
 - Serve as social workers and nurses
 - Navigating the fragmented health care and LTSS systems
- More diverse families
 - Multicultural
 - LGBT
- More women in the workplace
 - Nearly half today, up from 33% in 1960



Nearly half (46%) of family caregivers are carrying out health-related tasks in the home

- With little training or preparation
- Doing tasks that used to be done only by licensed health care professionals
 - Managing multiple complex medication schedules
 - Bandaging and wound care
 - Tube feedings
 - Managing catheters
 - Giving injections
 - Operating complicated medical equipment
 - Using sophisticated technology in the home

Source: S.C. Reinhard, C. Levine, and S. Samis, *Home Alone: Family Caregivers Providing Complex Care*, AARP Public Policy Institute and United Hospital Fund, 2012.



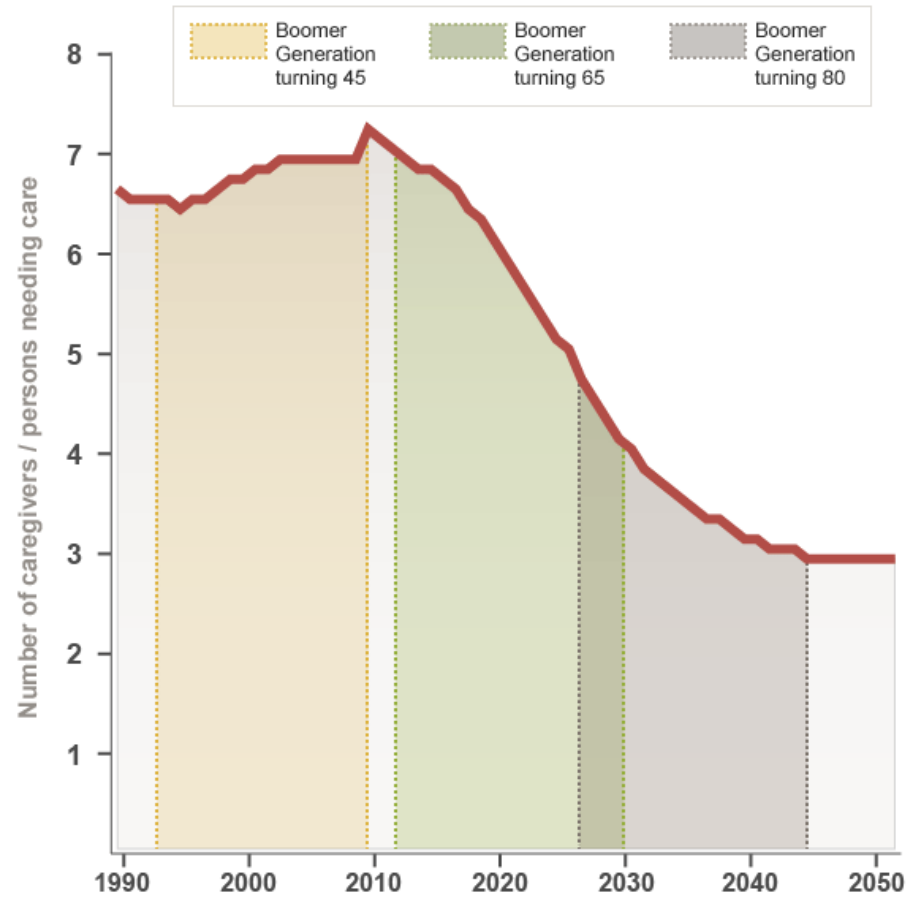
Caregiving in the U.S. 2015

- Only 1 in 3 (32%) family caregivers said a doctor, nurse or social worker ever asked them about what was needed to care for their relative/close friend
- Half as many (16%) said a health provider had asked what they need to care for themselves.



You Take Care of Mom, But Who Will Take Care of You?

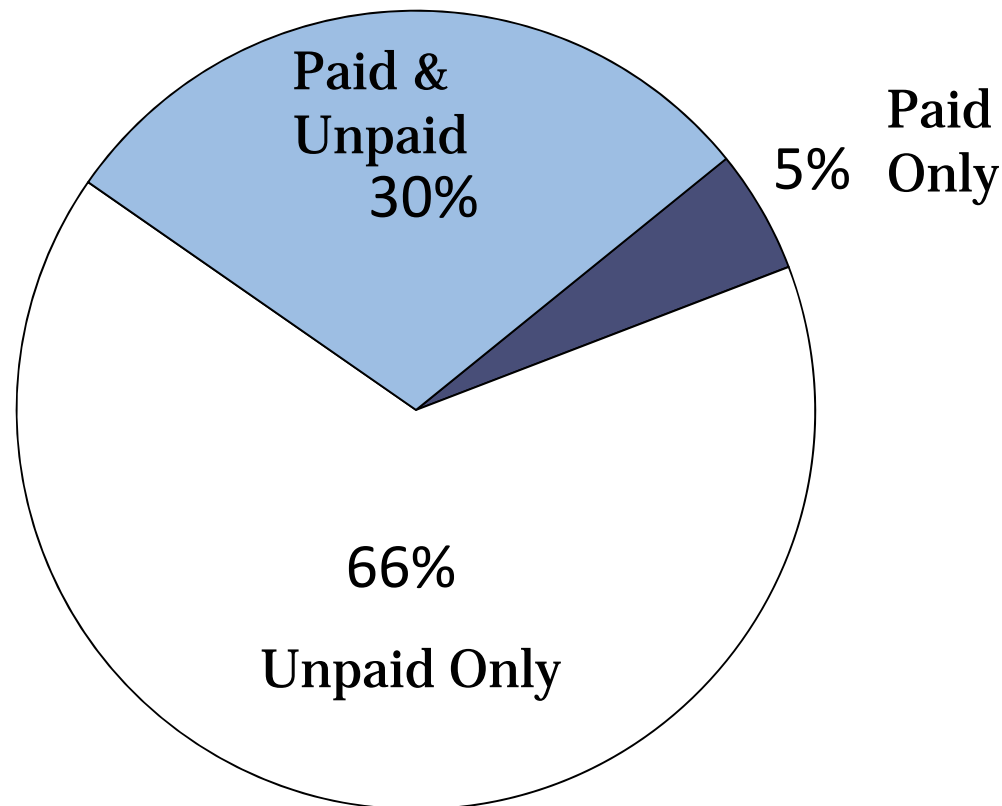
Caregiver Support Ratio



Who are Family Caregivers and What do they Do?



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



Data Source: 2011 National Health and Aging Trends Study.

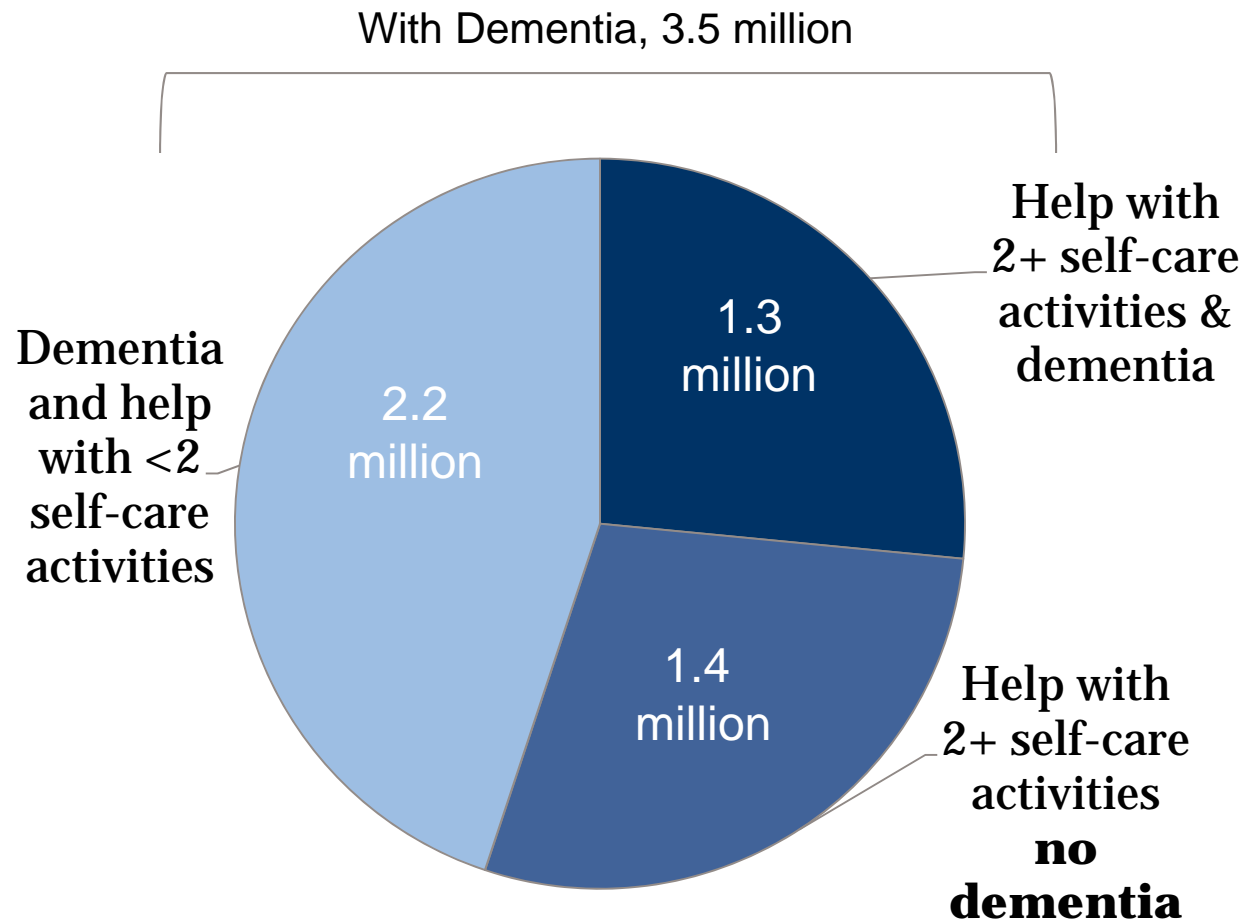
A Snapshot: Who are Today's Family Caregivers of Older Adults?

- 60% female; 40% male
- All ages: <45@17%; 45-64@45%; 65-74@22%; 75+@16%
Baby Boomers, GenXers, Millennials are 84% of caregivers
- 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

Estimated Prevalence and Economic Value of Family Caregiving for Older Adults

- About 17.7 million adults are family caregivers for people age 65+ with physical, mental, cognitive, or functional limitations (2011)
 - www.nationalacademies.org/caregiving
- Economic value of their unpaid contributions was approx. \$234 billion in 2011
 - Higher than total paid LTSS (\$192 billion in 2011)
 - More than 4 times expenditures for paid HCBS (\$58 billion in 2011)
 - <https://www.cbo.gov/publication/44363>

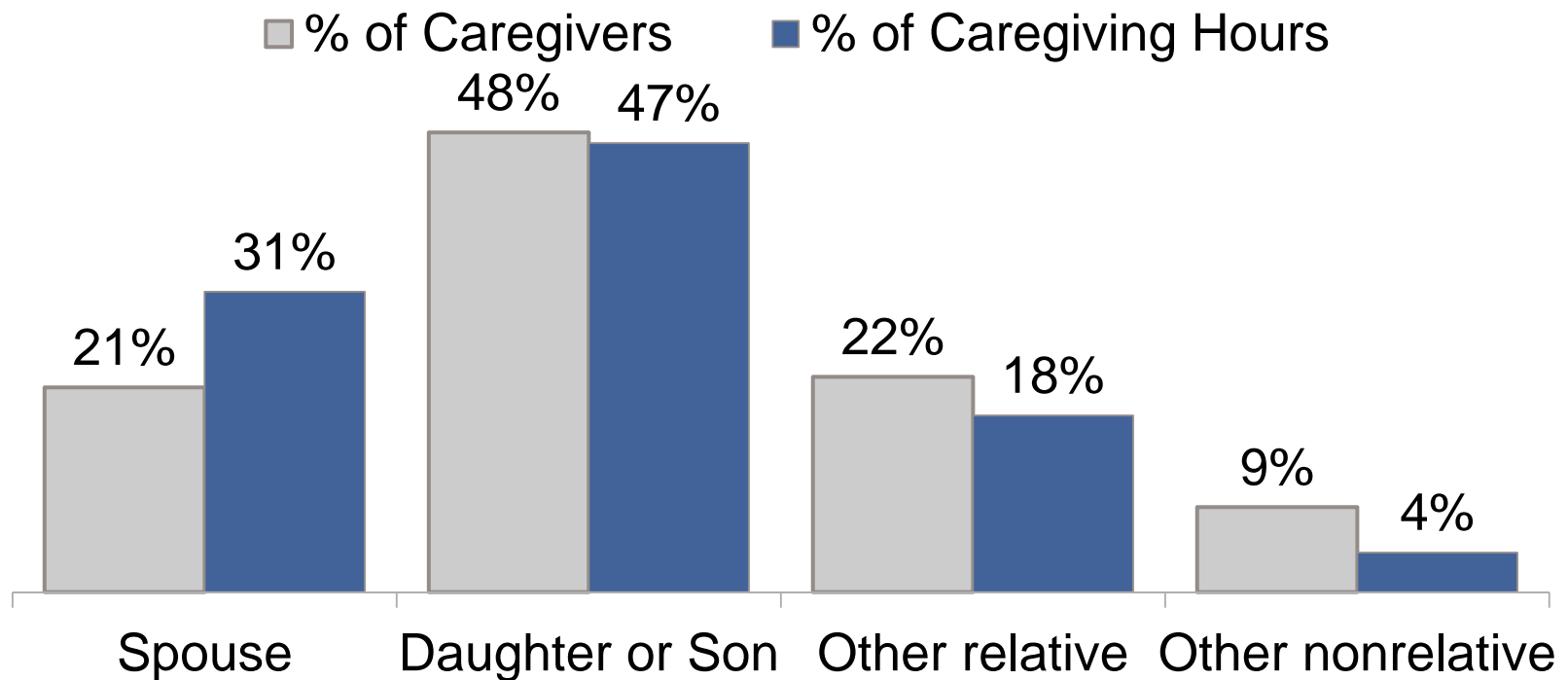


8.5 million caregivers provide help to 4.9 million high-need older adults (persons with dementia and/or 2 or more self-care needs), 2011

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

Family Members Comprise the Majority of Caregivers and Majority of Caregiving Hours to Older Adults



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

Family Caregivers Provide a Wide Array of Care

Provide emotional support and companionship

Help with household tasks (paying bills, preparing meals)

Carry out intimate, personal care (bathing, dressing)

Arrange for and provide transportation

Administer and manage multiple medications and other medical/nursing tasks

Identify, arrange, and coordinate services and supports

Hire and supervise direct care workers

Implement care plans

Communicate with health professionals

Serve as "advocate" during medical appointments and hospitalizations

Act as "care coordinator" during transitions

Discussion

- To get a better sense of the room
- Do these national statistics resonate?
 - What does your state look like in terms of:
 - Who are the family caregivers?
 - The growing care gap?
 - Is there anything surprising here?

What are the Challenges Facing Family Caregivers?

Costs of Caregiving: Families at Risk

- Family caregiving comes at substantial costs to the caregivers themselves
- A vulnerable and at-risk population that the health care and LTSS systems neglects
 - Physical health risks
 - Emotional strain/mental health problems (depression)
 - Social isolation
 - Financial burdens
 - Workplace issues
 - Retirement Insecurity
- Family caregiving is now viewed as a public health concern

The Health Impact of Caregiving is Highly Individual and Dependent on Personal and Family Circumstances

- For some, caregiving instills confidence, provides meaning and purpose, 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

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, 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.

Family Caregiving 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
 - 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

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

\$6,954

Average Out of Pocket Expenses for Family Caregivers in 2016

Family Caregivers Provide \$470 Billion in Unpaid Care

Source: Valuing the Invaluable 2015 Update: Undeniable Progress, but Bigs Gap Remain, AARP Public Policy Institute

More than three in four family caregivers (78%) are incurring out-of-pocket costs as a result of caregiving

78%

\$11,923

Average Out of Pocket Expenses for Long-Distance Caregivers in 2016

20%

Family caregivers are spending, on average, nearly 20% of their income on caregiving activities

Discussion

- Anything here jump out at you?
- Do you have stories to share around your own experience of caregiving and the various strains?

Building Supports

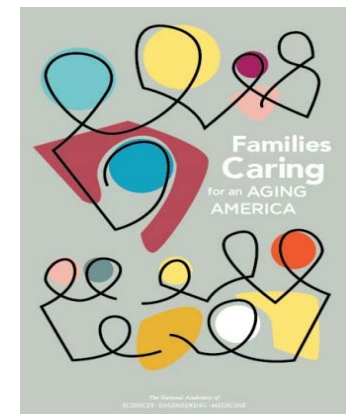
**Federal Efforts to
Recognize and Support
Family Caregivers**



Families Caring for an Aging America: **Findings**

- Although an intensely personal issue, family caregiving has become an urgent public policy issue, linked to important social, health, and economic goals
 - Raises serious concerns about the state of family caregiving for older adults in the U.S.
 - Calls into question practices that assume the availability of a family caregiver without adequate support services
 - Asserts that any truly person-centered care must also be *family-centered* and include the family caregiver.

www.nationalacademies.org/caregiving



Families Caring for an Aging America: **Recommendations**

1. The Secretary of HHS—working with the Secretaries of Labor and Veteran’s Affairs and others—should create and implement a National Family Caregiver Strategy
2. States should learn from states that provide services and supports to caregivers—and implement similar programs
3. The Secretaries of HHS, Labor and VA 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 of the above actions should explicitly address the diversity of older adults and their family caregivers.

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)
- Forum to engage Members of Congress and staff about family caregiving and LTSS issues
- Helps build champions and create an environment and context conducive to reaching bipartisan solutions.

RAISE Family Caregivers Act

- Recognize, Assist, Include, Support and Engage Family Caregivers Act (S. 1028)
- Requires development, maintenance and updating of an integrated strategy to recognize and support family caregivers
- Bi-Partisan Bill
 - Introduced in Senate by Senators Collins (R-ME) and Baldwin (D-WI)
- Passed the 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)
 - Referred to House Education and Workforce Committee

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.



Building Supports



**Potential State Levers to
Recognize and Support
Family Caregivers**

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 and affordable evidence-based caregiver 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

The Long-Term Services and Supports State Scorecard



- Concise performance tool to put long-term support and services (LTSS) policies and programs in context, prompt dialogue, and spark action
- Multidimensional approach to comprehensively measure performance over time
- Target areas for improvement
- View from a consumer perspective

www.longtermscorecard.org

The Vision: A High-Performing LTSS System

The *Scorecard* measures across 5 dimensions of LTSS system performance:

1. Affordability and Access

- Consumers can easily find and afford services, with a safety net for those who cannot afford services

2. Choice of Setting and Provider

- A person-centered approach allows for consumer choice and control of services

3. Quality of Life and Quality of Care

- Consumers are treated with respect and preferences are honored when possible, with services maximizing positive outcomes

4. Support for Family Caregivers



- Family caregivers' needs are assessed and addressed, so they can receive the support they need to continue in their roles

5. Effective Transitions

- Integration of health, LTSS and social services minimizes disruptions such as unnecessary hospitalizations, institutionalizations, and transitions between settings.

Scorecard Dimension: Support for Family Caregivers

In a high-performing LTSS system, the needs of family caregivers are assessed and addressed so that they can continue in their caregiving role without being overburdened.

Selected Indicators:

- Having paid family leave and paid sick days
- Having a caregiver assessment
- Having Caregiver Advise, Record, Enable (CARE) Act legislation

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State Workplace Policies for Family Caregivers

Paid Family Leave

- 5 States +DC
 - CA (2002), NJ (2008), RI (2013), NY (2016), DC (2017), WA (2017)

Paid Sick Days

- 8 States + DC
 - CT (2012), DC (2013), OR (2015), CA (2015), MA (2015), AZ (2016), VT (2016), WA (2017), RI (2017)



State Policies *for* Caregiver Assessment

- The 2017 LTSS State *Scorecard* finds that 33 states now conduct some form of caregiver assessments about the family caregiver's own health and well-being
 - Up from 15 states in 2014
 - Most caregiver assessments occur in the smaller family caregiver support programs, rather than the larger Medicaid HCBS programs

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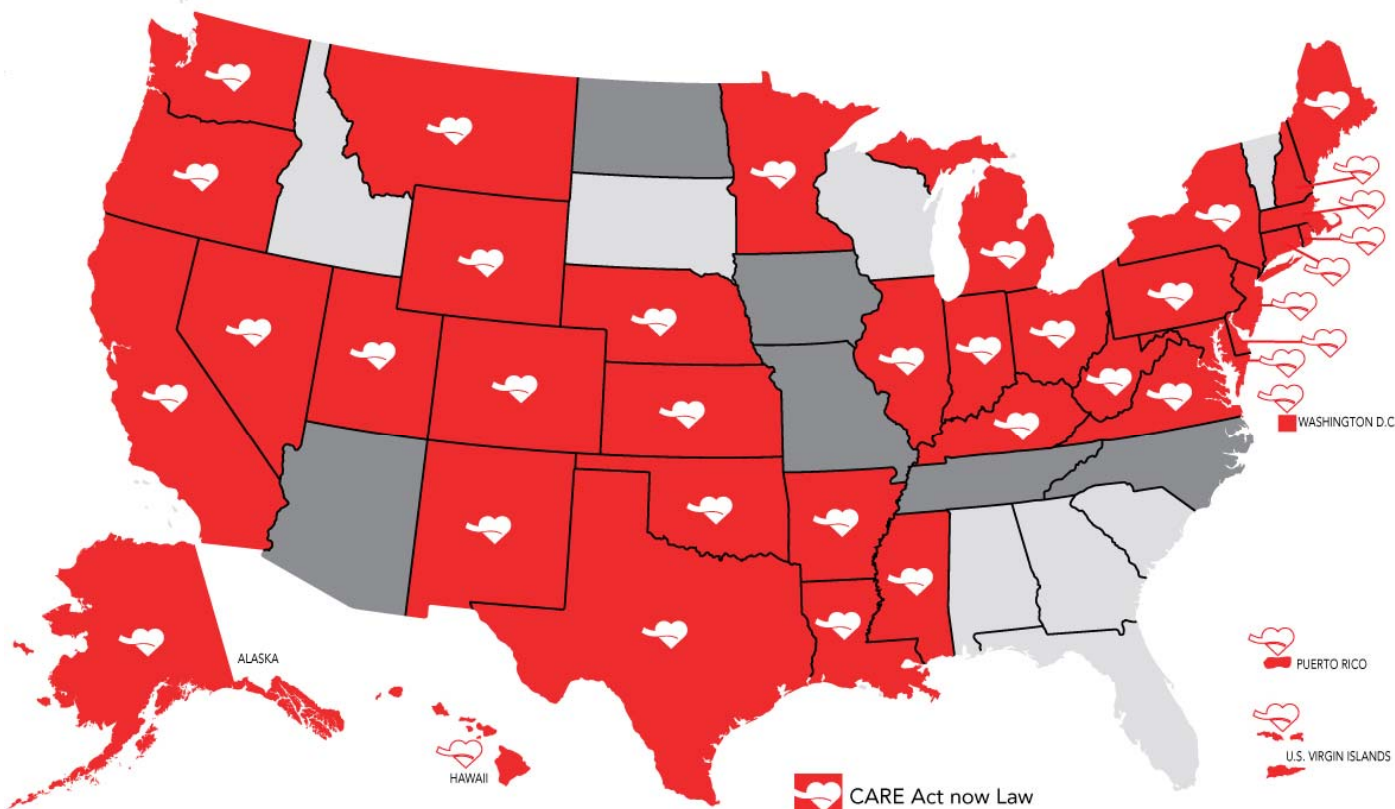
Translating Research Into Policy: The CARE Act

- 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!



The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.



CARE Act goes into effect:
 Oklahoma, 11/5/14; Colorado, 5/8/15; New Jersey, 5/12/15; West Virginia, 6/8/15; New Mexico, 6/17/15;
 Mississippi, 7/1/15; Virginia, 7/1/15; Arkansas, 7/22/15; Connecticut, 10/1/15; Nevada, 10/1/15; Maine,
 10/15/15; Puerto Rico, 12/31/15; California, 1/1/16; Indiana, 1/1/16; New Hampshire, 1/1/16; Oregon,
 1/1/16; Illinois, 1/27/2016; Utah, 2/10/16; Nebraska, 3/30/16; Virgin Islands, 3/30/16; New York, 4/23/16;
 Washington, 6/9/16; Wyoming, 7/1/16; Washington D.C., 7/6/16; Michigan, 7/12/16; Louisiana, 8/1/16;
 Maryland, 10/1/16; Alaska, 1/1/17; Delaware, 1/1/17; Minnesota, 1/1/17; Rhode Island, 3/14/17; Ohio,
 3/20; Pennsylvania, 4/20/17; Kentucky, 6/29/17; Hawaii, 7/1/17; Montana, 10/1/17; Kansas, 7/1/2018;
 Massachusetts, TBD; Texas, TBD

**Updated on 6/10/2017

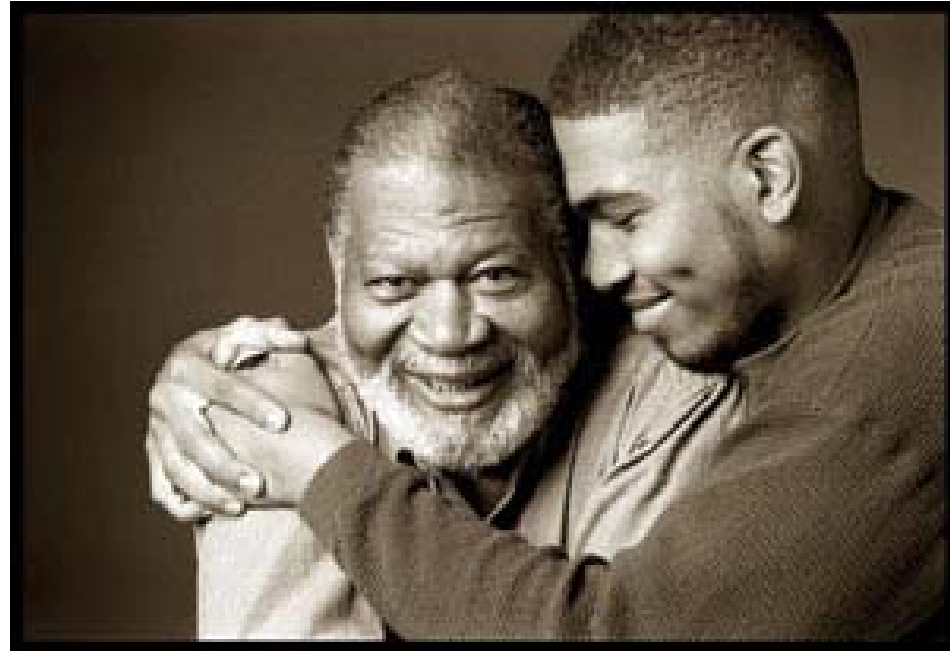
I ♥ Caregivers **AARP** Real Possibilities

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
- **NM's State Plan for Family Caregivers of Older Adults** (2014)
 - Creates a state plan to address the challenges faced by family caregivers
- **TN's TennCare CHOICES Program**
 - Requires managed care orgs. to conduct caregiver assessments (2015), and ensure that 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' own health and well-being in caring for older adults at home with LTSS needs
- **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 supportive services.

Examples of Other Potential State Policy Levers

- Consumer-directed programs
- Caregiver tax credits
- Telehealth
- Other initiatives?



“ What we need... is for our nameless problem to be plucked out of the realm of the personal and brought into full public view, where help can find us.”

-- Jonathan Rauch, “Letting Go of My Father,” *The Atlantic*, April 2010.

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Real Possibilities

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