

FAMILY CAREGIVING: Trends, Policies, and What's Next for States

Reforming States Group Pre-Conference on Family Caregiving

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Caregiver Trends and Policies are Changing — and the Pace of Change is Accelerating

*“There is more policy and program
change in the past five
years than in the past 25 years.”*

Briefing Overview

Five Questions:

- Who are family caregivers?
- What do they need?
- What are the key trends for caregiving?
- What are current federal and state policies?
- What are the recommendations for change at the state level?

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.



Isn't caregiving just something families have always done?



Yes . . . and . . . No

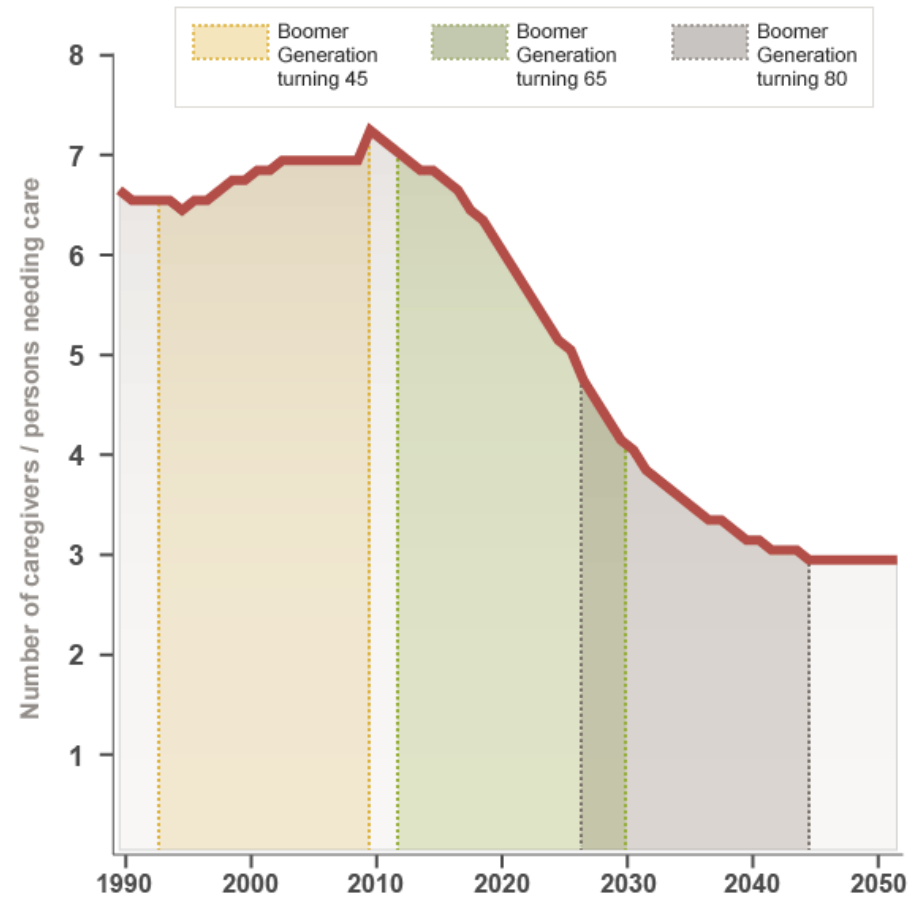
What has changed in the last 50 years?

- Increased life expectancy (1965: 67M/72W; 2017: 77M/81W)
- Improvements in managing complex health conditions
- Development of community-based services and the pendulum shift from facilities to home care
- Change in women's roles, education and employment
- Decrease in number and size of families

Expectations of unpaid caregivers are greater now and growing.

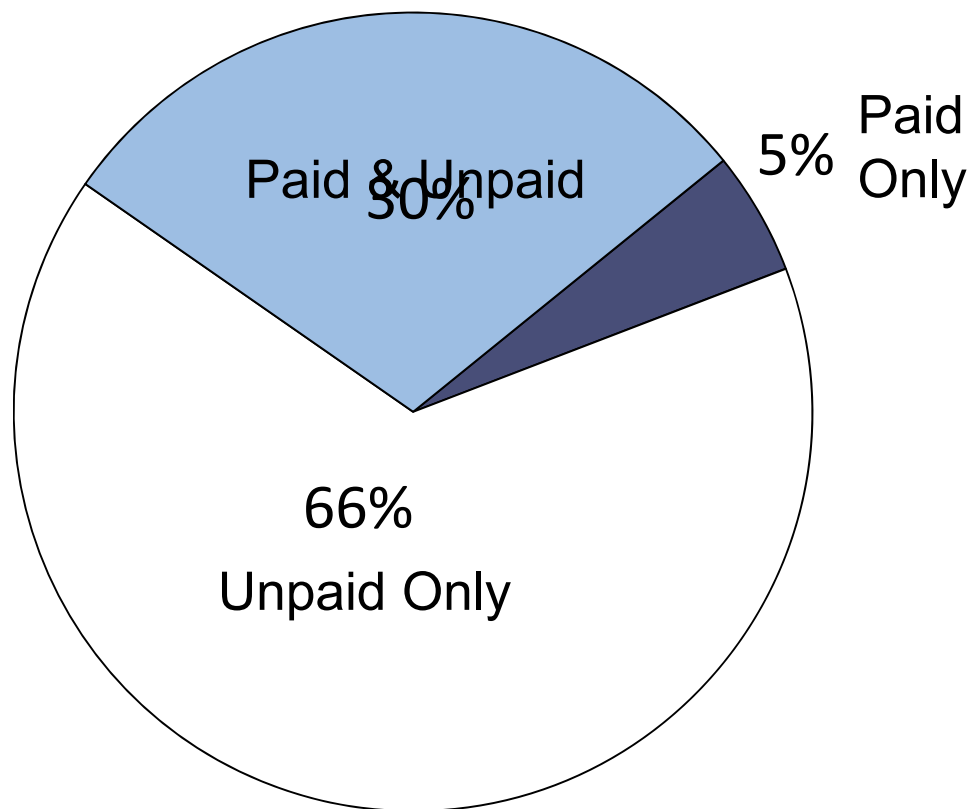
You Take Care of Mom, But Who Will Take Care of You?

Caregiver Support Ratio

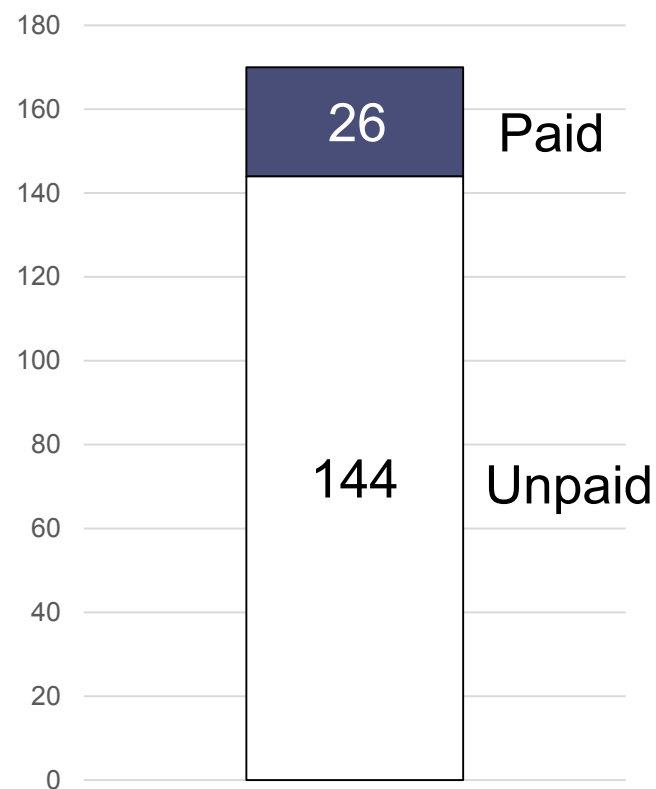


Most LTSS Is Provided by Family and Unpaid Caregivers

Community-Dwelling Older Adults
With Disabilities by Type of Help



Mean Hours of Help
Per Month



Data Source: 2011 National Health and Aging Trends Study.

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

- 60% female; 40% male
- Ages: <45@17%; 45-64@45%; 65-74@22%; 75+@16%
- *Baby Boomers, GenXers, Millennials are 84% of caregivers*
- Spouse: 21%; Adult child: 48%; Other rel: 22%; Other: 9%
- More than half (50.3%) work at a paying job
- Average hours of care/week: 19.5 hours
- 60% provide care for 4+ years

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

- More than 1 in 3 (34%) care for someone with dementia
- 17% of older adults with health and functional needs reside in rural areas
- Rural caregivers have specific challenges (K. Buckwalter, University of Iowa):
 - Fewer adult children due to out-migration for employment
 - Usually have less formal education, more likely to be poor, more likely to be self-employed or in small business
 - Health services less accessible, less specialized
 - Community based services and support less available
 - Institutionally based care more prevalent

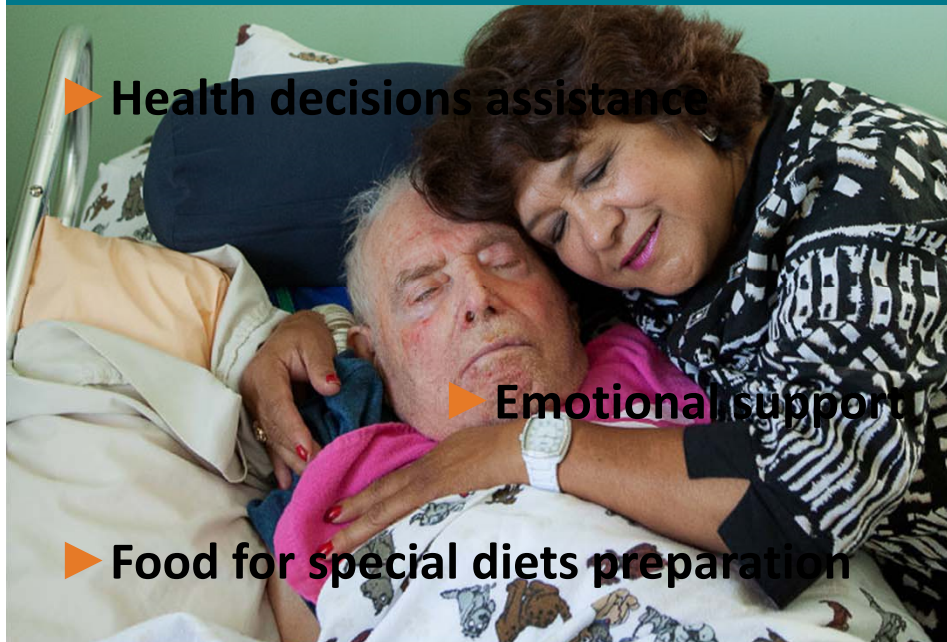


- ▶ Health insurance advocate
- ▶ Financial management
- ▶ Household tasks
- ▶ Family member coordination



- ▶ Medical tasks
- ▶ Medication management
- ▶ Medical equipment operations

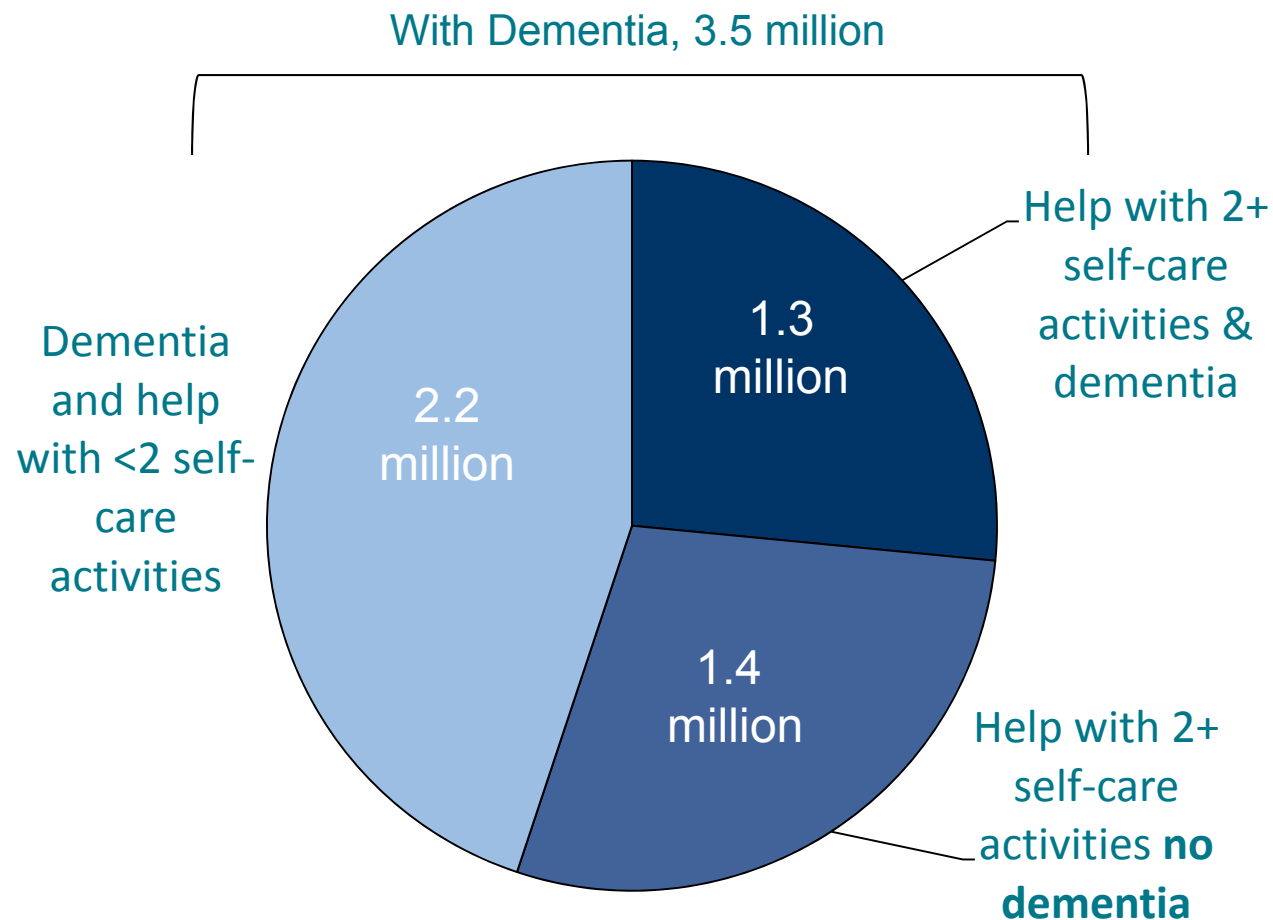
What do family caregivers provide?



- ▶ Health decisions assistance
- ▶ Emotional support
- ▶ Food for special diets preparation



- ▶ Transportation
- ▶ Personal Care
- ▶ Social activities organizing
- ▶ Care coordination



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

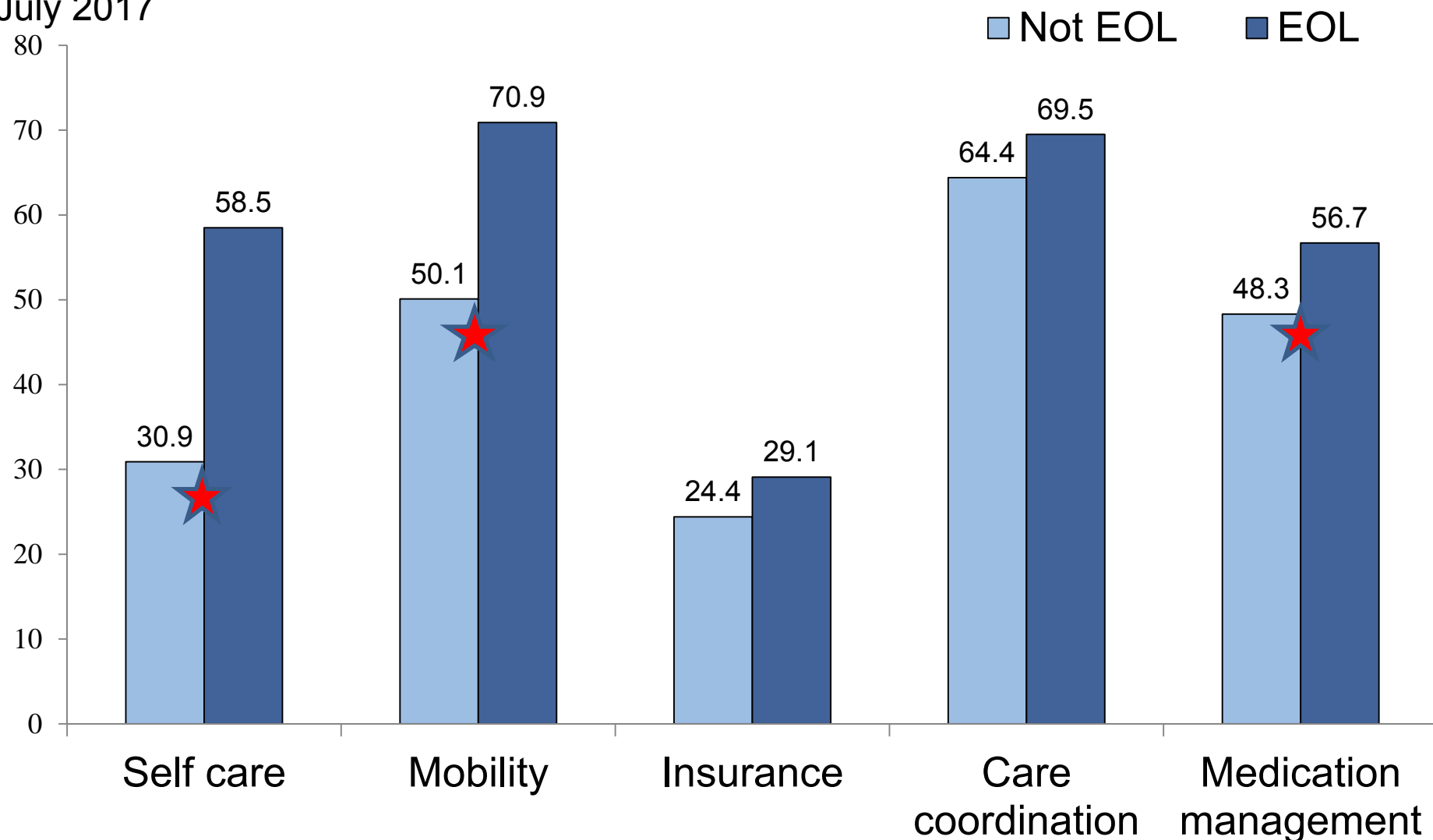
NOTES: As reported by Medicare beneficiaries age 65 and older (or their proxy) for the prior month. Self-care activities include bathing, dressing, eating, toileting, or getting in and out of bed. "Probable dementia" includes individuals whose doctor said they had dementia or Alzheimer's disease and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

HealthAffairs

A National Profile of End-of-Life Caregiving in the United States

By Katherine A. Ornstein, Amy S. Kelley, Evan Bollens-Lund, Jennifer L. Wolff

July 2017



Source: 2011 National Health and Aging Trends Study and National Study of 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; lost career opportunities
 - Retirement Insecurity
- Family caregiving is now viewed as a public health concern

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.

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.

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>

What Services Do Caregivers Need?

Caregiver-Centric Services:

- Information on wide range of topics related to caregiving
- Uniform assessment and reassessments as needed for the family caregiver including the person needing assistance
- Based on the assessment, an action plan with tailored information and services
- Training on personal care, behavior management, stress reduction,
- Short term groups on decision making, handling difficult behavior, coping skills
- Legal and financial consultation
- Short term counseling
- Consumer-directed respite care
- In-person and online peer support groups
- Personal electronic record that includes information and services

What Are the Characteristics of Service Delivery?

Services Should:

- Build on and be tailored to the family caregiver through assessment
- Have services responding to the multiple needs of the family caregiver
- Be consumer-directed
- Able to respond to changing needs over time
- Be accessible for employed, isolated by geography or caregiving demands and at the convenience of the caregiver
- Have data available that documents outcomes

Emerging Trends in Service Delivery

- Moving towards person-and-family-centered care within health care and social services systems
- Emphasis on using evidence-based interventions that can scale, meet the time demands of caregivers and have be adapted for diverse populations
- Use of technology by family caregivers mirrors general population trends for adults in the US: 90% have internet access; 75% have broadband in the home; 77% own smartphones; 10% have smartphones only. Rural access lags behind and needs to be addressed.
- Family caregivers use technology for health and service information, for home care tasks, and to receive support and services
- Data systems are a basic requirement of partnerships between health care and social service systems

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

Current Federal Policies Supporting Family Caregivers

- **Older Americans Act, National Family Caregiver Support Program (2000)**
 - **Family caregiver as client** – culture change in aging network
 - Provides caregiver support services (e.g. family counseling, support groups, training, respite care)
- **Lifespan Respite Act (2006)**
 - Expands and enhances respite services in the states
- **Caregivers and Veterans Omnibus Health Services Act (2010)**
 - Provides training and education, support, medical care and coordination for eligible family caregivers

Current Federal Policies that Recognize and Support Family Caregivers (cont'd)

- New provisions in **Medicare** and **Medicaid** provide first steps to better identify and engage family caregivers in health care and LTSS
 - **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)

Current Active Proposed Federal Policies

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.

Current Active Proposed Federal Policies: RAISE Family Caregivers Act

- **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 Senate (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)

Current Active Proposed Federal Policies: 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.



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.

State Workplace Policies for Family Caregivers

Paid Family Leave

- 5 States +DC
 - CA (2002), 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 Employment Anti-Discrimination Laws

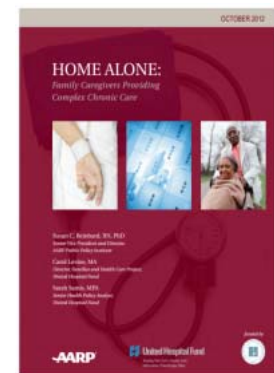
- As of 2017, just four states have such laws enacted
 - Connecticut
 - Delaware
 - District of Columbia
 - Minnesota

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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!



State Policies for Family Caregivers

States with Alzheimer's Plans

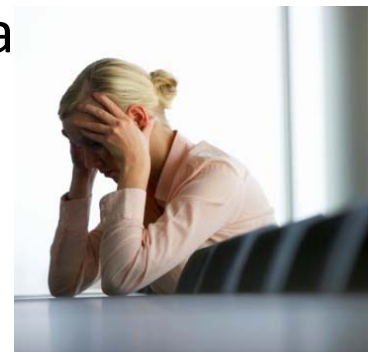
- Nearly every state

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 Certifica

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



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.

State Policy Ideas

General:

- Ask one simple question: Are family caregivers identified and involved in (proposed long term health/services, program rule changes, regulations, legislation)?
- Are family caregivers on advisory councils to state departments on Alzheimer's/dementia, palliative care, Olmstead, state aging, Medicaid, health care facilities, etc.
- There is no one policy that addresses all needs of caregiving families – it is a package of policies that address the variety of issues families face daily

State Policy Ideas *continued*

Specific:

- Caregiver Tax Credits
- Tax Check-Off funding to Support Research or Innovation
- Uniform Adult Guardianship Certificates
- CARE Act
- Paid Family Leave and/or Sick Days
- Expansion of telehealth and/or wireless or Internet access for underserved or rural communities
- Employment Anti-Discrimination
- Financial Assistance to Employed Caregivers (HI)
- Increased Appropriations for Caregiver Support Services
- Change Nurse Delegation Rules to Allow for Home Health to Perform Medical Tasks



Family Caregiver Alliance (www.caregiver.org) offers education, services, research, and advocacy based on the real needs of family and informal caregivers. Founded in the late 1970s, FCA is the first community-based nonprofit organization in the United States to address the needs of families and friends providing long-term care for loved ones at home.

National Center on Caregiving (NCC) was established by FCA to advance the development of high-quality, cost effective programs and policies for caregivers in every state. NCC sponsors the Family Care Navigator, a state-by-state resource locator designed to help caregivers find support services in their communities.

Bay Area Caregiver Resource Center — operated by FCA for the six-county San Francisco Bay Area — provides support to family caregivers. FCA's staff of family consultants through education programs and direct support offer effective tools to manage the complex and demanding tasks of caregiving.

FCA CareJourney is a secure online solution for quality information, support, and resources for family caregivers of adults with chronic physical or cognitive conditions such as Alzheimer's, stroke, Parkinson's, and other illnesses.

FCA Learning Center (launch: November 2017) will be the new online home for caregiver education. With resources from FCA's vast library of caregiver knowledge, users of the learning center will be able read, watch, listen, and learn from anywhere at anytime.

800.445.8106 | 415.434.3388 | info@caregiver.org



facebook.com/FamilyCaregiverAlliance



youtube.com/CAREGIVERdotORG



twitter.com/CaregiverAlly

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