Research to Action: Advancing Support For Family Caregivers.

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Family Caregiving Today
Family Caregiving: Then

- Family caregivers traditionally provided assistance with ADLs and IADLs.

- Caregiving was an almost entirely private affair.

- Multigenerational households were more common.
The Care Gap

• In 2010, the caregiver support ratio was more than 7 potential caregivers for every person in the high-risk years of 80-plus.

• By 2030, the ratio is projected to decline sharply to 4 to 1.

• It is expected to fall to less than 3 to 1 in 2050, when all boomers will be in the high-risk years of late life.
Family Caregiving: Now

• The role of family caregivers has dramatically expanded.

• This includes performing medical/nursing tasks once only provided in hospitals.

• Smaller households and family sizes places caregiving responsibility on fewer people.

• Family caregiving is being addressed by policymakers.
Today’s Family Caregivers

• More than 40 million Americans perform the family caregiving role each year to someone age 18+.

• Family caregiving cuts across gender, age and race/ethnicity.
  – Four in ten of these family caregivers are men.
  – Multicultural groups over-index in caregiving.
  – One in four is a millennial.
Today’s Family Caregivers

- Family caregivers today support people with various conditions, and do so in a variety of contexts.
  - Close to 1 in 3 support someone in a rural area.
  - 15% of care recipients are veterans.
  - More than half (60%) are employed.
  - 1 in 5 care for a person with a mental health or emotional issues.
Today’s Family Caregivers

- Older family caregivers (65+) are more likely to care for a spouse or partner, while those under 65 are more likely to care for a parent or parent-in-law.

- Spousal caregivers are more likely to be higher hour caregivers, and more often perform complex ADL and medical/nursing tasks.
Family Caregivers Provide $470 Billion in Unpaid Care

Average Out of Pocket Expenses for Family Caregivers in 2016:

$6,954

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

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

$11,923

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

20%
National Academies’ Report


• Funders use report to help inform grant-making strategy and identify new opportunities.
Social Needs Care Providers and Family Caregiving

- Right now, several professional fields help provide care for the social needs of older adults.
  - Social workers
  - Nurses
  - Community health workers
  - Case/care managers
  - Attorneys
  - Physicians

- **Family caregivers** are critical in providing this support as well and should be included as part of the social needs care team.
Everyday Realities of Family Caregiving: Employment
All Types of Family Caregivers Work

- About 6 in 10 (61%) family caregivers are employed.
- This group cuts across age, race and gender.

By generation, Millennials are the most likely to work while caregiving.

- Millennials: 73%
- Generation X: 66%
- Boomers: 62%
- Silents: 20%

At the same time, more than half of employed family caregivers are 50+.

- 50+: 51%
- 18-49: 49%
All Types of Family Caregivers Work

- The intersection of work and caregiving cuts across age, race and gender.

Multicultural family caregivers are more likely to be employed.

More than half of men and women family caregivers work.

- Hispanic: 68%
- AAPI: 67%
- African American: 60%
- White: 56%
- Men: 66%
- Women: 55%
Employed Family Caregivers Help With a Wide Range of Tasks

• More than one in four (28 percent) report helping their relative or friend with three or more activities of daily living (such as bathing, dressing, or using the toilet).

• Employed family caregivers perform medical/nursing tasks at almost the same rate (45%) as those who do not work (46%).
  – These family caregivers often perform these complex tasks with little or no support or instruction from health professionals.
Impact of Caregiving on Employment

• Most family caregivers (61%) report experiencing at least one negative impact on their work as a result of caregiving.
• The most frequent impact is going to work late or leaving early (49%), followed by taking time off from work (15%) or reducing hours (14%).
• Family caregivers who spend more time (21+ hours per week) caregiving are more likely to experience negative impacts at work.

• Additional reading: https://www.aarp.org/ppi/info-2016/the-dual_pressures-of-family-caregiving-and-employment.html
The RAISE (Recognize, Assist, Include, Support and Engage) Family Caregivers Act

- The RAISE Family Caregivers Act would authorize the development and maintenance of a National Strategy to Support Family Caregivers.
- The National Strategy would be developed by the secretaries of health and human services, labor, housing and other key government and non-government stakeholders.
- The National Strategy is a key recommendation from the National Academies’ report on family caregivers of older adults.
- The RAISE Family Caregivers Act is under consideration by Congress. It has passed the Senate, and has been introduced in the House of Representatives.

Paid Family Leave

- Six states and D.C. have enacted paid family leave policies that include time off to care for an older relative or person with disabilities.
- A new paper from AARP Public Policy Institute reviews these and discusses the implications of PFL (or lack thereof) for working family caregivers.
Employment Anti-Discrimination Laws

• The 2017 LTSS State Scorecard tallied which U.S. states have laws that specifically protect family caregivers from employment discrimination as a protected classification under law.

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

• Additional reading: http://longtermscorecard.org/
State Unemployment Insurance Laws for Family Caregivers

• Available to family caregivers who voluntarily leave work to care for an ill or disabled family member
  – Must be deemed “good cause” (i.e., voluntarily quit job due to compelling family circumstances) to be eligible to receive benefits
  – Benefits available for up to 1-year

• As of 2016, 25 states enacted unemployment insurance laws
• Laws are permanent; would require legislative repeal
• Help from $7B in federal stimulus in 2009 to modernize unemployment insurance programs
The Credit for Caring Act

- This act would provide a tax credit for family caregivers with out-of-pocket caregiving-related expenses.
- Family caregivers who spend at least $2,000 on caregiving could receive a tax credit up to $3,000.
- Applies to family caregivers of people of all ages.
- This new policy proposal has broad support in Congress, but has not yet been passed.

AARP Solution: Employer Toolkit

• To help support family caregivers at work, AARP partnered with the Northeast Business Group on Health to develop a toolkit for employers.

Strategies for Employers

- These are some strategies identified in the employer toolkit

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<td>Extend Telehealth Benefits</td>
<td>Be Sensitive to Privacy Needs</td>
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<td>Provide Useful Tips To Ease The Burden</td>
<td>Tailor Communications to Increase Engagement</td>
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<td>Connect Employees With Specialist Guidance</td>
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Everyday Realities of Family Caregiving: Health Care
Family Caregiving and Complex Care

- About half (46%) of family caregivers perform complex medical/nursing tasks.
  - Medication management
  - Assistance with mobility
  - Help with wound care
  - Help with incontinence care

- Family caregivers are critical to helping coordinate care for the people they support, and often are not included on the care team during hospital stays.
The CARE Act: Supporting Family Caregivers During Hospital Stays

• AARP developed model legislation based on the *Home Alone* findings— the Caregiver Advise, Record and Enable (CARE Act)

• The law supports patients and family caregivers of all ages, and for any diagnosis

• Law in 40 states and territories— and counting!
The National CARE Act Scan

• AARP is leading a national scan of states and health systems to identify and diffuse promising practices and determine where gaps remain

• Interviews with cross-disciplinary professionals, and family caregivers. Examples include:
  – Nursing
  – Pharmacy
  – Physical Therapy
  – Information Technology

• Focused on key areas of implementation including:
  – Identifying the Family Caregiver
  – Information Technology and Electronic Health Records
  – Identifying Training Resources
Learnings from the National CARE Act Scan

• The implementation process allowed hospital staff and leadership to standardize how to interact with family caregivers throughout the discharge process

• Some hospitals are training registrars and other staff to differentiate among the “next of kin,” “guardian,” or “family caregiver” who may be the same person or two or three different people

• Individual hospitals and health systems have begun certain processes or initiatives that show promise and could scale nationally
  – One hospital, for example, expanded its call center capacity to create a 24/7 toll-free line for family caregivers to call for support post-discharge
Payment Reform and Family Caregivers

• Medicare payment innovations are moving U.S. health care towards value-based care, rather than volume-based care.

• These payment models, such as bundles and Accountable Care Organizations, will likely lead to health systems relying more on family caregivers.

• Most of these policies are at the federal level (through Medicare), but other payers (such as Medicaid) could experiment these policies at the state level.
Additional Information and Resources
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