
Family Matters: Transforming Policy and Practice for Caregiving Families in an Aging America

2017 Elder Friendly Futures Conference

Lynnwood, WA

September 15, 2017

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Can't we talk about
something more
PLEASANT?



ROZ CHAST
A MEMOIR

Four Main Points

- ❖ Caregiving today takes place in a radically different world from that of our grandparents' generation.
- ❖ The U.S. is facing an unprecedented care gap.
- ❖ Time to shift the mindset from family care as an individual responsibility to a shared, societal responsibility.
- ❖ We need to treat family caregiving with a new urgency and make it a national priority.

Family Caregiver

Broad Definition

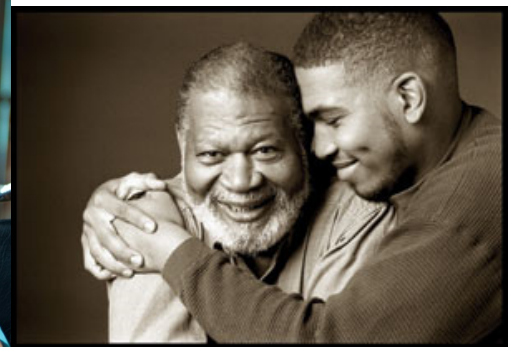
- ❖ Any relative, partner, friend or neighbor who has a significant personal relationship with, and who provides a broad range of assistance for, an older person or an adult with a chronic, disabling, or serious health condition.



Family Caregiving in the “Old Days”



The “New Normal”



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

The Increasing Complexity of Family Caregiving Today: Three Trends

More family caregivers are:

❖ In the labor force

➤ Especially older women

❖ Providing complex care in the home

➤ Estimated 46% do medical/nursing tasks

❖ Coordinating care between the silos of healthcare and LTSS



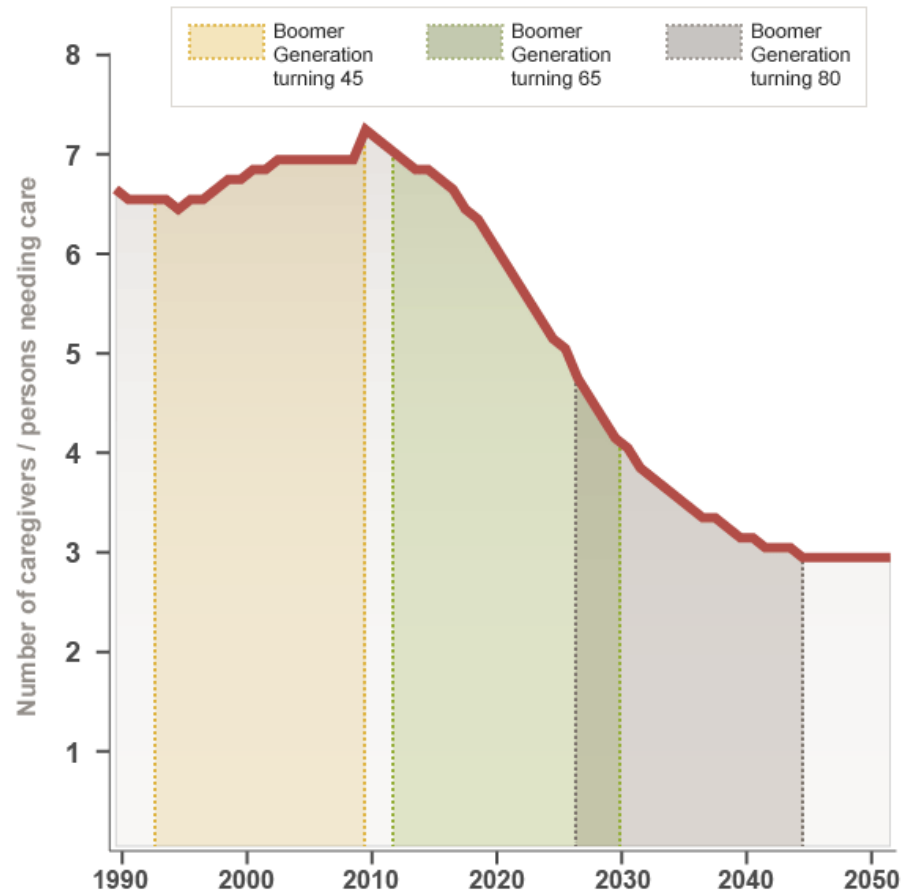
Caregiving in the U.S. 2015

- ❖ 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



What May Happen When the “Bowling Alone” Generation becomes an Aging Alone Generation

“Baby boomers will enjoy much less ‘informal’ eldercare than their parents did. Much of the research on eldercare today includes the Greatest Generation, which had a high level of social capital and relied on friends, relatives, and religious organizations for care as they aged. Baby Boomers have much less social capital than the previous generation—including fewer spouses and children, fewer friends, and fewer religious ties. In short, Boomers are entering retirement with one-third less social capital than their parents enjoyed which can lead to social isolation and less reliable care as they age.”

- Robert Putnam, Professor of Public Policy at Harvard University and author of *Bowling Alone*. Testimony before the Joint Economic Committee on the state of social capital in America, May 17, 2017.

Shifting the Mindset

<u>Stay at home women</u>	<u>Employed women</u>
Men <u>aren't</u> family caregivers	<u>40 percent</u> of family caregivers are men
<u>Older people and adult daughters</u> are caregivers	25 percent of caregivers are <u>millennials</u>
Family caregivers only help with <u>ADLs/IADLs</u>	They do ADLs/IADLs <u>AND</u> Care Coordination, Med/Nursing and other Health Mgt. Tasks

Shifting the Mindset

Patient	Person
Health care <u>only</u>	Health care and <u>LTSS</u>
Reward <u>volume</u> of services	Reward <u>value</u> of services
Family caregivers are the <u>problem</u>	Family caregivers are a <u>solution</u>
Family caregivers are “ <u>resources</u> ” for the person	Family caregivers can be “ <u>clients</u> ”
<u>Patient</u> /Person-centered	Person- and <u>family</u> -centered
<u>Informal</u> caregivers	Family and unpaid caregivers (broadly defined)
LTSS is an <u>individual, family</u> responsibility	LTSS is a <u>shared, societal</u> responsibility
<u>Piecemeal</u> help for families	Consistent, <u>national</u> strategy

Moving Forward

- ❖ More needs to be done to transform our public policies and private sector initiatives to adjust to the realities of the changing family and family situations
 - Especially for low and middle-income families who are largely left on their own.



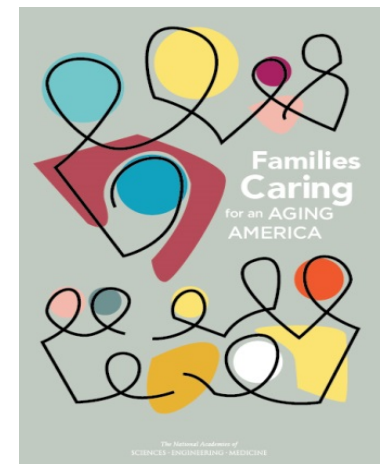
Families Caring for an Aging America

Committee on Family Caregiving for Older Adults

A Report of *The National Academies of
Sciences, Engineering and Medicine*

September, 2017

www.nationalacademies.org/caregiving



Families Caring for an Aging America

- ❖ Although an intensely personal issue, family caregiving has become an urgent public policy issue, linked to important social, health, and economic goals
- ❖ The committee's work:
 - 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



Families Caring for an Aging America: **A Vision for the Future**

No less than a transformation in policies and practices resulting in a society in which family caregivers:

- ❖ Have their own health and well-being considered
- ❖ Have rights and protections in health care, LTSS, and in the workplace
- ❖ Have their preferences, needs, and strengths recognized and supported by health and social service professionals
- ❖ Are supported as caregiving changes and evolves



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.

Building Supports

How can public policy help?

Assisting Caregivers Today (ACT) Caucus

- ❖ Launched March 2015
- ❖ 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
- ❖ Help build champions and create an environment and context conducive to reaching bipartisan solutions.

RAISE Family Caregivers Act

- ❖ Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act (S. 1028)
- ❖ Introduced by Senators Collins (R-ME) and Baldwin (D-WI)
- ❖ Bill would require the development of a national strategy to recognize and support family caregivers
- ❖ Passed the Senate HELP Committee unanimously in May

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.



Transforming Practice: The Home Alone AllianceSM

- Collaborative of public, private, and nonprofit sector organizations dedicated to creating solutions that support family caregivers performing complex care tasks.
- A key resource from the Home Alone AllianceSM are instructional videos.
- Find our videos and resources at:

www.aarp.org/nolongeralone



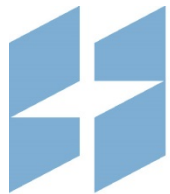
The Home Alone AllianceSM Founding Partners



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Questions?

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