
6th Annual International Carers Conference

Family Caregiving: Research, Policy, Practice

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AARP

- Nonprofit, nonpartisan organization
- 38 million members
- Mission: Help people strengthen communities and fight for the issues that matter most to families.
- Family caregiving essential to mission

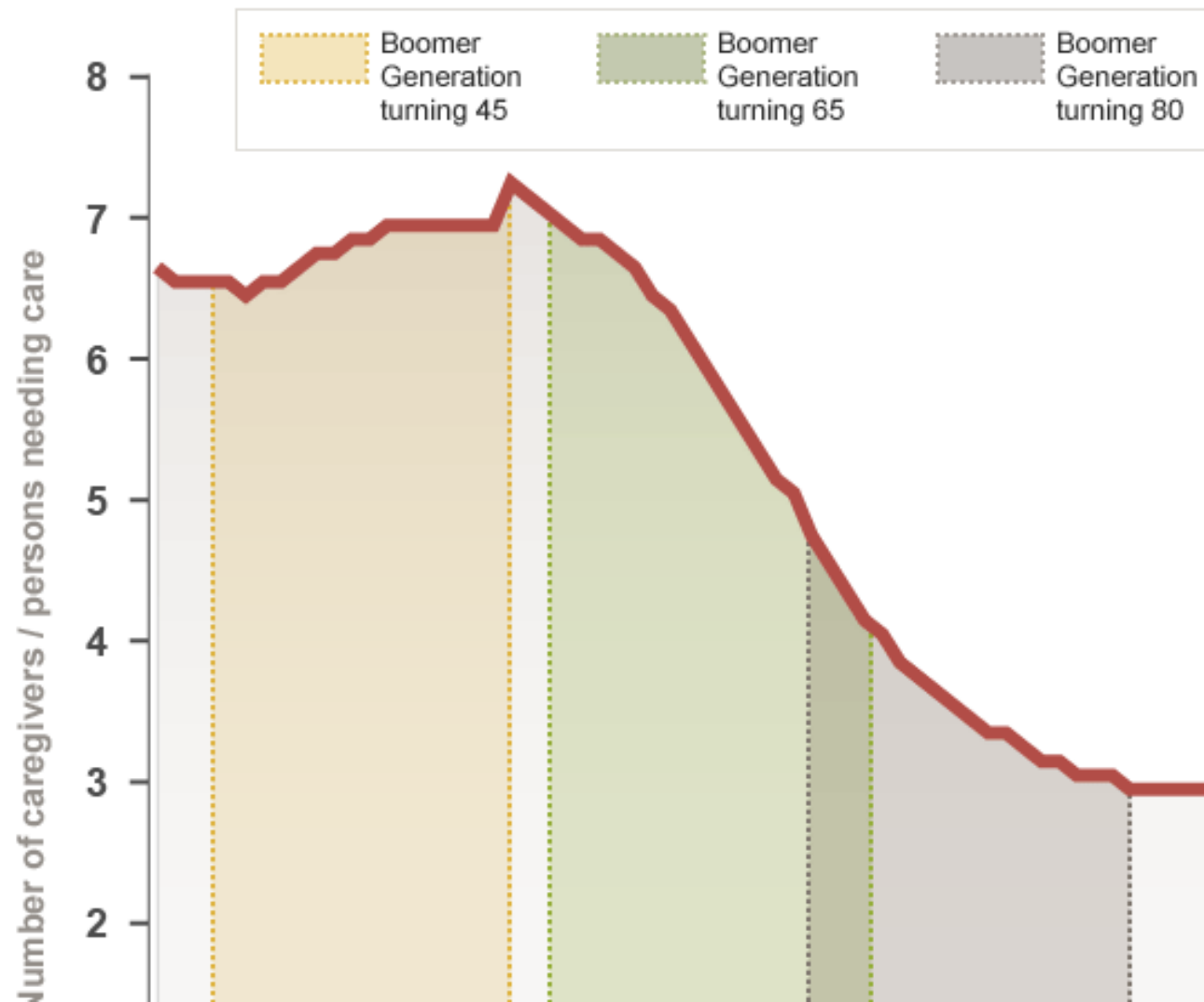
AARP Public Policy Institute

- Think Tank for AARP
 - Conduct **Research** to stimulate public debate.
 - Promote sound, creative **Policy**.
 - Shape **Practice**
 - **Professionals Supporting Family Caregivers**
 - **Center to Champion Nursing in America**

Demographics

- In July 2015, world population = 7.3 billion
12.3% > age 60; 1.7% > age 80
- Globally, 60+ will more than double by 2050 triple by 2100
- In Europe, 24% already 60+; 34% by 2050
- 28% of all people 80+ now live in Europe

Caregiver Support Ratio



Valuing the Invaluable

- In 2013, about **40 million** family caregivers in the U.S. provided care to an adult with limitations in daily activities
- The estimated economic value of their unpaid contributions was about **\$470 billion in 2013**
 - **↑** from an estimated **\$450 billion in 2009**

How Much is \$470 Billion?



Time

Putting a
Dollar
Value
to Family
Caregiving

AARP[®] Real
Possibilities

TIME COMMITMENT



Caregivers spend an average of

18 hours per week

providing care to a family member.

60%

Family caregivers caring for an adult while employed full or part time.

Provide **21+ hours** of family care per week while working a job.

22%

2015 AARP Public Policy Institute

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Work-Related

**Putting a
Dollar
Value
to Family
Caregiving**

AARP® Real
Possibilities

WORK COMMITMENT

**1 in 4 workers
age 25+
are family
caregivers.**

72%

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workers 40+ that say
allowing work flexibility
for caregiving would
help improve work/life
balance.

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Financial

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Dollar
Value
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FINANCIAL COMMITMENT

68%

Family caregivers who say they have to use their own money to help provide care to their relative.



39%

felt financially strained.

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Growing Complexity of Care

SEPTEMBER 2012

HOME ALONE:

*Family Caregivers Providing
Complex Chronic Care*



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AARP

 **United Hospital Fund**
Shaping New York's Health Care
Submissions: Publications Policy

funded by



Home Alone Research

- AARP Public Policy Institute and United Hospital Fund collaborated on **first in-depth national survey** of family caregivers in this area

This report documents:

- What **medical/nursing tasks** family caregivers do;
- What they find difficult;
- **Who trains/guides them**; and
- Impact on their quality of life.

Medical/Nursing Tasks

- Managing complex medications (Poly meds, Injections)
- Prepare special food diets
- Wound care
- Changing catheters
- And more...

Recognition and Support from Healthcare Professionals

- Better communication
- More preparation for transitions across settings
- Assessment of the caregivers' needs
 - Rarely are family caregivers asked “How are *you* doing? How are *you* managing?”
- Recognition as “team member”
 - Intimate knowledge of care recipient
 - Acquired care skills
 - Desire to be partners

Higher-Hour Caregivers

- 32% of caregivers are higher-hour
- Provide 21 hours of care/week
- Average = **62 hours/week**
- High burden of care
- Report having “no choice”



Multicultural Family Caregivers

- More likely to be higher-hour
 - Asian American Pacific Islander: 37%
 - African American/Black: 39%
 - Hispanic/Latino: 40%
- Existing gap in research
- Surprisingly little research
- Current methods problematic

A Call to Action

- CARE Act
- Home Alone Alliance
 - Caregiver Training Videos
- Working Caregivers
- Paid Family Leave
- Respite
- RAISE Act

CARE Act

- Opportunity for patient to identify a family caregiver to include in the patient- and family- centered care process...in the record
- Notification of discharge
- Teaching/anticipatory guidance for family caregiver expected to perform medical/nursing tasks

CARE Act

- Give support to nurses and other health and social service professionals to do what their professional standards of practice require them to do
- Stimulate new thinking on how to anticipate patient and family questions and pro-actively support them
- Reduce hospital re-admissions

Home Alone Alliance

- Alliance of private, non profit, and academic organizations
- Change the field, change the culture
- Provide quality training videos for family caregivers performing complex tasks

Family Caregiver Training Videos

- Provide training vehicle on medical/nursing tasks
- Audience: Family Caregivers and Nursing Students
- First series focusing on medication management

Working Caregivers Need Help

- 70% who perform medical/nursing tasks reported that caregiving impacted job
- 34% left their job due to lack flexible work hours
- Employers acting to retain experienced workers:
 - Manager training
 - Flexible Time
 - Backup care

Paid Family Leave

- The U.S. has no national paid family leave program
- Three States have a paid family leave program (California, New Jersey, Rhode Island)
- Federal Program for Unpaid Family Leave (FMLA)
 - Most families can't afford to take unpaid leave

Respite

- Lifespan Respite Act
 - Currently underfunded
 - Assists family caregivers with access to respite services
 - Trains and recruits respite workers
 - Enhances coordinated systems of community-based programs

RAISE Family Caregivers Act

- **Recognize, Assist, Include, Support and Engage**
- **Bi-Partisan Senate Bill**
- **Requires development, maintenance and updating of an integrated national strategy to recognize and support family caregivers by the HHS Secretary**

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