

Family Caregiving in an Aging America

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Family Caregiving Story

Mrs. P

- 89 year-old widow
- Retired secretary, lives alone
- 5 chronic conditions; dementia
- 6 physicians
- Requires significant personal assistance to maintain independence
- Medicaid only pays for 4 hrs/day of home health aide
- 3 recent hospitalizations for poorly controlled diabetes
- Confused by care, meds
- Poor quality of life

Only Daughter: Carol

- Age 59, divorced, 2 grown children
- Lives 1 hour from Mrs. P.
- Consumed with role of “care coordinator” and “provider”
- Increasingly anxious and depressed; high blood pressure
- Scared to manage multiple meds, prepare special diets
- Reduced work to ½ time; lost health and retirement benefits
- High out-of pockets costs for home care help
- Considering nursing homes

Overview of Family Caregiving



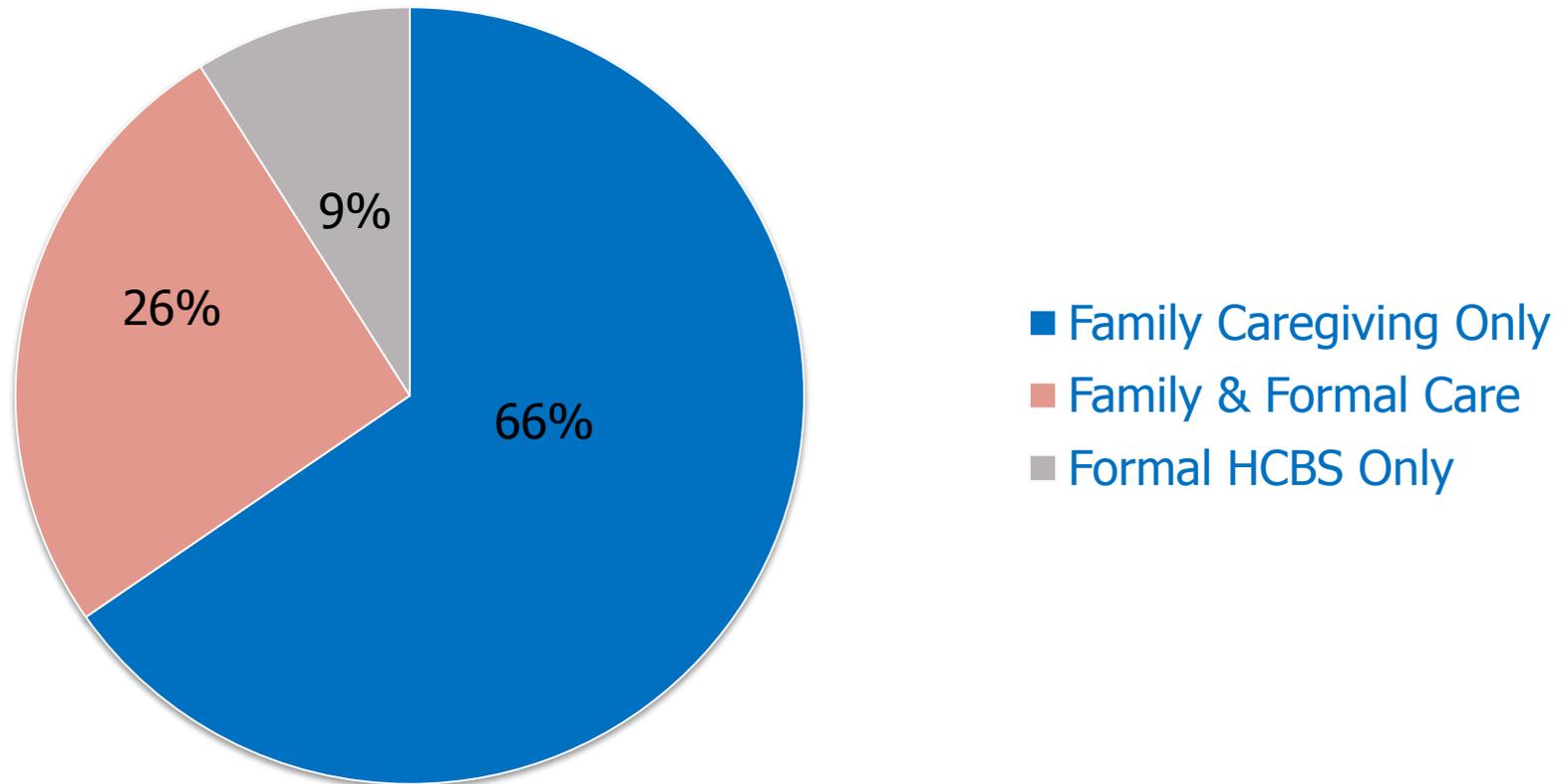
Family Caregiver – *Broad Definition*

- Any relative, partner, friend or neighbor who has a significant relationship with, and who provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.
- The “average” U.S. caregiver is a 49-year-old woman who works and spends nearly 20 hours/week providing unpaid care to her mother for nearly 5 years.



Long-Term Services and Supports (LTSS) Are a Family Matter

Distribution of Older Adults (65+) Receiving LTSS in the Community, by Type of Care



Source: P. Doty (2010). The evolving balance of formal and informal, institutional and non-institutional long-term care for older Americans: A thirty-year perspective. *Public Policy & Aging Report*, 20 (1):3-9.

The Big Disconnect

- Lack of understanding of the complexity of caregiving today, and the human toll on those receiving AND giving care...*until it happens to you*
- Many family/friends don't identify themselves as family caregivers
- Family members are often invisible in the care process
- Family members are *providers* and *coordinators* as well as *receivers* of services and supports
 - Not just a "resource" for the care recipient
 - May also be a "client"–
 - an individual who may need training and support too
 - Practical, emotional, and financial help



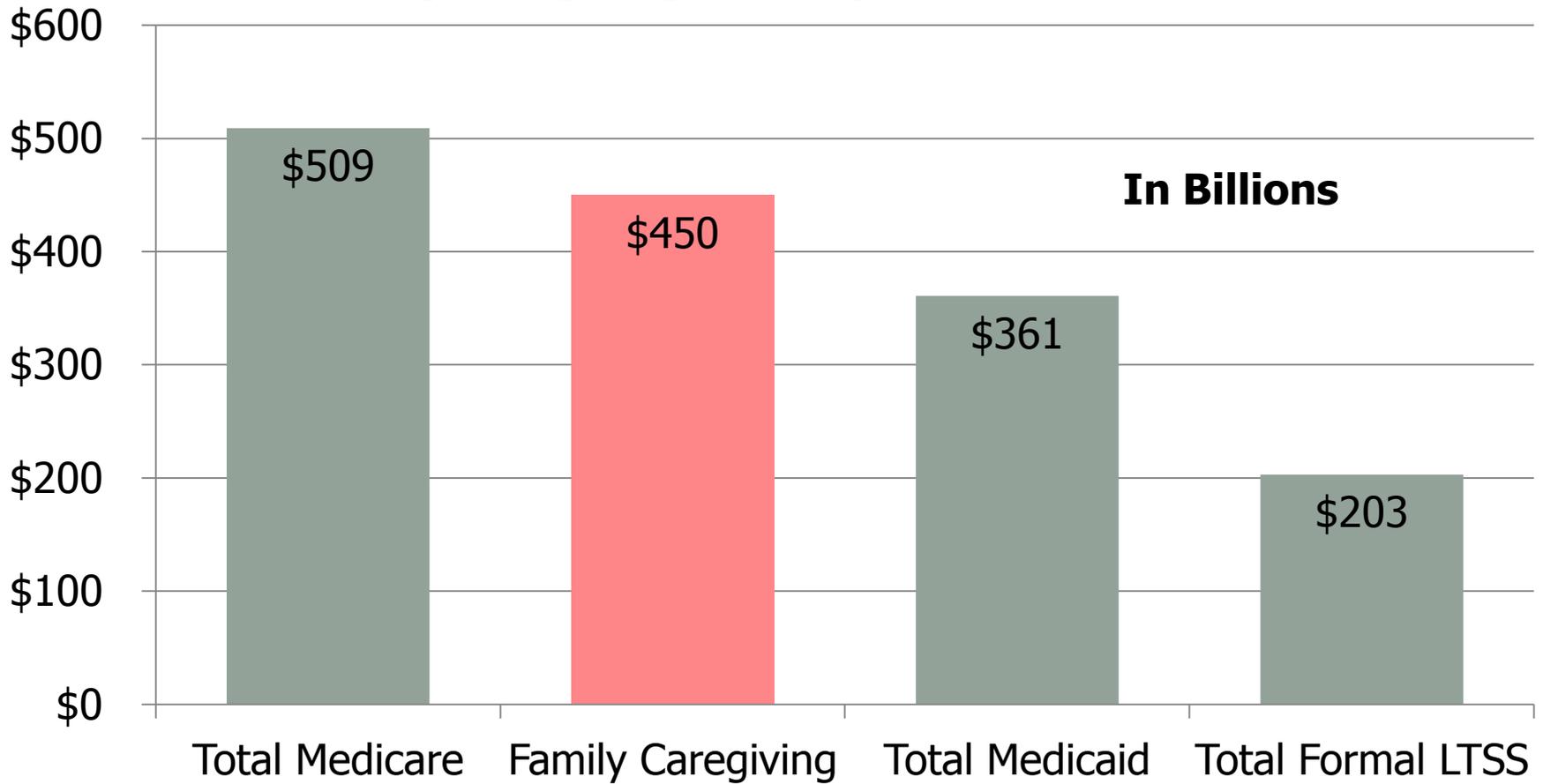
Valuing the Invaluable

- About **42.1 million** family caregivers in the U.S. provide an estimated **40 billion hours** of care to an adult with limitations in daily activities at any given point in time
- The estimated economic value of their unpaid contributions was about **\$450 billion in 2009**

Source: L. Feinberg, S.C. Reinhard, A. Houser, and R. Choula, Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving (Washington, DC: AARP Public Policy Institute, June 2011)

How Much is \$450 Billion?

Family Caregiving is as big as Medicare and Medicaid



Characteristics of Caregiving

- 1 in 5 adults
- More than 8 in 10 are caring for relative or friend age 50+
- Predominantly female (2 in 3)
 - Typically wife or adult daughter
- 31% care for 2 or more people
- 61% working



Family Caregiving in the “Old Days”



What's Different About Caregiving Now than in the Past?

More complicated, costly, stressful and demanding than at any other time in human history

- Longer duration of caregiving
- 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 women in the workplace
 - Nearly half today, up from 33% in 1960

What's Different About Caregiving Now than in the Past?

Changing composition of families & households

- More long-distance caregiving
- Increasing diversity
- Delayed marriage and childbirth

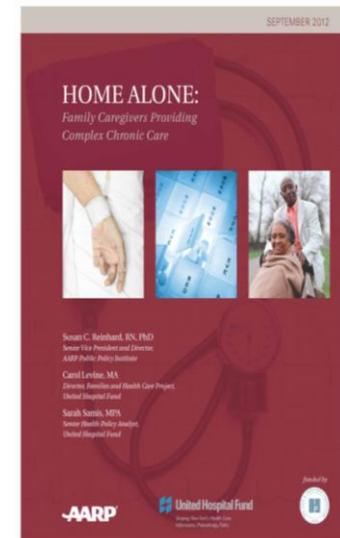
- High rates of divorce
 - Divorce rate of 50+ pop. doubled between 1990 and 2010

- Fewer adult children (smaller families)
 - The % of frail elders (age 85+) without any surviving children is projected to increase from 16% to about 21% in 2040.

- Increasing numbers of childless women
 - Nearly 20% of women are childless today; 10% in 1970

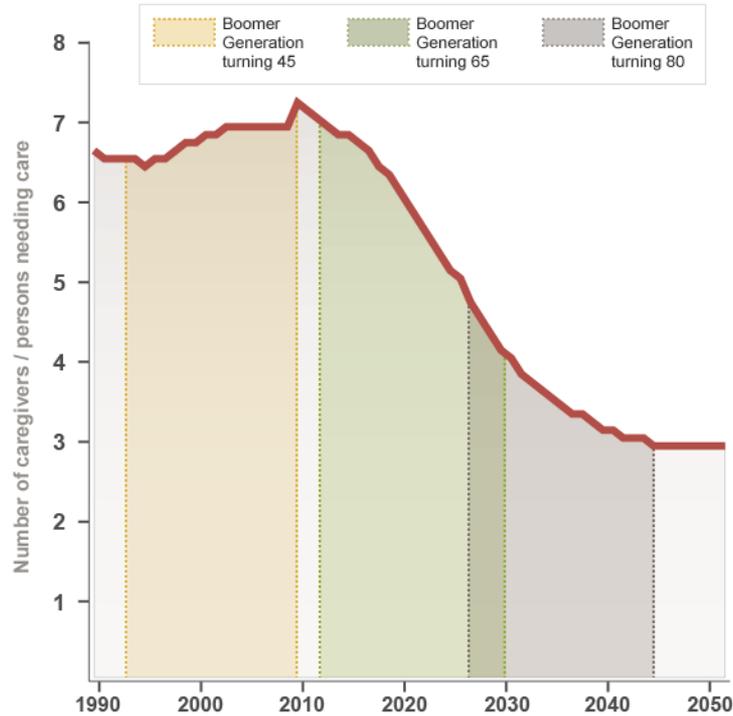
What's Different About Caregiving Now Than in the Past?

- Nearly one-half (46%) of family caregivers are carrying out health-related tasks
- New research shows health-related tasks are performed in the home with little training or preparation
 - Managing complex medication schedules
 - Bandaging and wound care
 - Tube feedings
 - Managing catheters
 - Giving injections
 - Operating medical equipment
 - Using sophisticated technology in the home



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

Caregiver Support Ratio

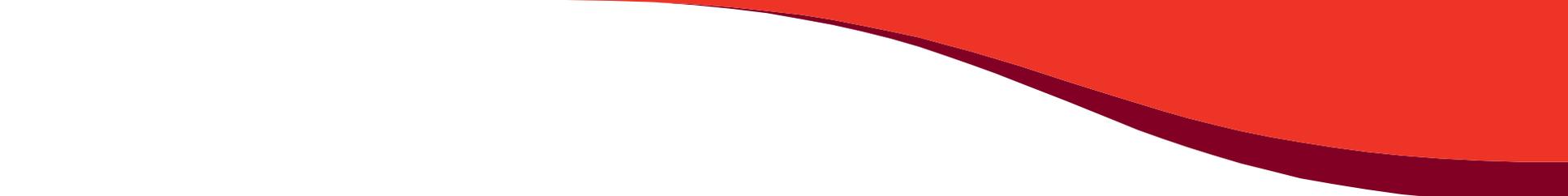


In **2010**, the caregiver support ratio was **more than 7 potential caregivers** for every person in the high-risk years of 80-plus.



In **2030**, the ratio is projected to decline sharply to **4 to 1**; and it is expected to further fall to less than **3 to 1** in **2050**.

POLICY ACTION: Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.



Challenges and Barriers Faced
by
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 neglect
 - 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

Costs of Caregiving: Families At Risk

Health Impacts

- Early research focused on mental health
- More recent studies find negative impacts on physical health
- An estimated 17% to 35% of family caregivers of adults rate their own health as fair to poor
 - Poorer physical health than non-caregivers (16%)
- Family caregivers to older relatives report higher levels of stress and poorer health than the population at large
 - More than half (55%) of family caregivers surveyed said they felt overwhelmed by the amount of care their family member needs

*(Source: American Psychological Association, *Stress in America: Our Health at Risk*, 2012)*

Costs of Caregiving: Families At Risk

Caregivers face chronic health problems of their own and health risks

- Heart disease
- Hypertension
- Stroke
- Poorer immune function
- Slower wound healing
- Sleep problems and fatigue
- Increased use of psychotropic drugs
- Premature death among highly stressed spouse caregivers



Costs of Caregiving: Families At Risk

Mental Health Problems

- Caregivers commonly experience strain and anxiety
- An estimated 40% to 70% of family caregivers of older adults have clinically significant symptoms of depression
- Caring for persons with dementia is especially stressful and challenging

Costs of Caregiving: Families At Risk

Greater Social Isolation

- Caregivers frequently experience social isolation from a loss of social contacts
- Over half (52%) say that their caregiving responsibilities take them away from friends or family members (NAC and AARP, *Caregiving in the U.S. 2009*)
- Caregivers who experience social isolation also experience high levels of stress

Costs of Caregiving: Families At Risk

Financial Burdens

- More than 1 in 4 (27%) caregivers of adults report a moderate to high degree of financial hardship from caregiving
(NAC and AARP, *Caregiving in the U.S. 2009*)
- About 1 in 5 (21%) women ages 18-64 say that caregiving for an aging relative strains their household finances
(*Kaiser Women's Health Survey*, May 2011)

Costs of Caregiving: Families At Risk

High Out-of-Pockets Costs

- Caregivers of adults age 50+
 - Spend, on average, more than 10% of their annual income on caregiving expenses (\$5,531)
 - Those with lowest incomes (less than \$25,000/year) spend more than 20%
 - Long-distance caregivers have the highest annual expenses (\$8,728)

(Evercare and National Alliance for Caregiving, *The Economic Downturn and its Impact on Family Caregiving: Report of Findings*, 2007).

Costs of Caregiving: Families At Risk

Impact of Caregiving on Work

- 74% of family caregivers have worked at a paying job at some point during their caregiving experience
 - 61% are currently employed
- Of those caregivers who are employed, 68% report making work adjustments because of caregiving
 - Arriving late/leaving early, reducing work hours, changing jobs, stopping work entirely
- Those most likely to make workplace accommodations:
 - Have the most intense level of caregiving (21+ hours of care/wk)
 - Experience a high burden of care
 - Live with the care recipient

(NAC and AARP, *Caregiving in the U.S. 2009*)

Working Family Caregivers: Lost Wages and Retirement

Lifetime income-related losses

*Family Caregivers age 50+ who leave the workforce
to care for a parent*

=

- \$324,044 for women
- \$283,716 for men

- **\$304,000**, on average, in lost income and benefits

Source: MetLife Mature Market Institute, *The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents*, June 2011



Policy Recommendations

Commission on Long-Term Care: Workforce Recommendations

Family Caregiving Prominence

- Require HHS to develop a national strategy to maintain and strengthen family caregiving
 - Focus on multi-sector strategies to support caregiving families
 - Not just government (federal and state)
- Include family caregivers in the needs assessment and care planning process
- Encourage expansion of caregiver interventions
 - Such as education and training and respite care

Missing from Commission's workforce recommendations:

- Adoption of caregiver-friendly workplace policies

Taking Care of Caregivers

Federal Policy Recommendations

Enact federal legislation to require the development of a national strategy to support family caregivers

Help family caregivers with the cost of care, such as through a tax credit

Extend the family caregiver assessment provision in the Medicaid HCBS state plan option [1915(i)] to other Medicaid HCBS authorities

Include family caregivers in individuals' health records and as essential members of the care team

Include family caregivers and their needs in the assessment and care planning processes

Preserve and increase funding for the National Family Caregiver Support Program and the Lifespan Respite Care Program

Improve access to leave for working caregivers by making improvements to the FMLA's provision of unpaid leave as well as improving access by creating paid leave

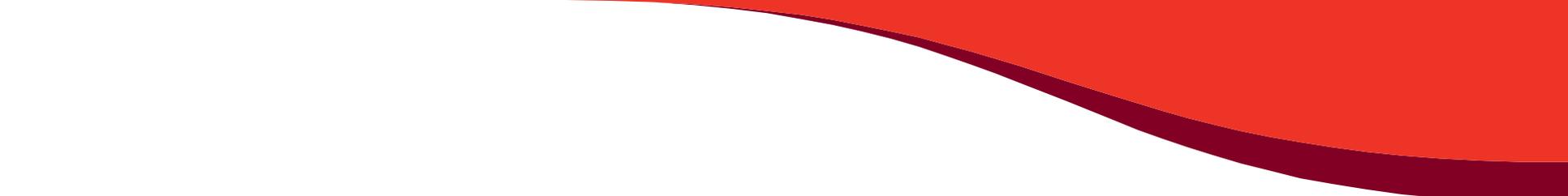
Taking Care of Caregivers

State Policy Recommendations

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- Support during hospital transitions
 - Removing barriers to practice and care
 - Respite Care
 - Workplace Flexibility
 - Technology
 - Access to Direct Care Workers
 - Caregiver Tax Credits

Take Aways

- The burden of chronic illness and disability affects the family as well as the individual
- Family caregiving is one of the least appreciated but most important issues the U.S. faces as our population ages
- Health care and social service professionals must fundamentally change the way they interact with family caregivers in daily practice
- The current heavy reliance on families to provide LTSS is unsustainable
- We must raise the visibility of and support for caregiving families to keep them from burning out.



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