

## POLICIES TO BETTER SUPPORT INFORMAL CAREGIVING



POLICY BRIEF

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The MacArthur Foundation Network on an Aging Society brings together scholars who are conducting a broad-based analysis of how to help the nation prepare for the challenges and opportunities posed by an aging society. Research focuses on how major societal institutions, including retirement, housing and labor markets, government and families, will have to change to support the emergence of a productive, equitable aging society. [www.agingnetwork.org](http://www.agingnetwork.org)

### Network members

**Director:** John Rowe  
Columbia University  
Mailman School of Public Health

**Toni Antonucci**  
Institute for Social Research  
University of Michigan

**Lisa Berkman**  
Harvard University  
School of Public Health

**Axel Boersch-Supan**  
Director, Munich Center for the  
Economics of Aging  
Max-Planck-Institute for Social Law  
and Social Policy

**Laura Carstensen**  
Stanford University, Center on  
Longevity

**Linda Fried**  
Dean, Mailman School of Public  
Health, Columbia University

**Frank Furstenberg**  
University of Pennsylvania,  
Department of Sociology & Population  
Studies Center

**Dana P. Goldman**  
Director, Leonard D. Schaeffer Center  
for Health Policy and Economics  
University of Southern California

**James Jackson**  
University of Michigan  
Institute for Social Research

**Martin Kohli**  
Visiting Scholar, Dept. of Demography  
University of California, Berkeley

**S. Jay Olshansky**  
University of Illinois at Chicago  
School of Public Health

**John Rother**  
President and CEO  
National Coalition on Health Care

For supporting evidence and deeper background on the issues raised in this brief, see the accompanying Network on Aging in Society backgrounder, “The Scope and Effects of Informal Caregiving.”

**Policy briefs in this series include:**

Supporting Informal Caregiving in an Aging Society

Ensuring Generational Cohesion in an Aging Society

Improving Health Care and Support for Older Americans

Promoting Productivity in an Aging Society

Promoting Lifelong Learning in an Aging Society

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The Scope and Effects of Informal Caregiving

Intergenerational Cohesion and the Social Compact

Improving Health Care and Support for Older Americans

Productivity in an Aging Society

The Scope and Benefits of Life-Long Learning

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Many individuals who provide assistance and support to family members do not consider themselves “caregivers.” Instead, they see themselves as just doing what a loved one would do for a parent or family member. However, they are indeed caregivers: providing necessary resources to their loved ones in order to keep them financially, physically, and emotionally supported. And they often do it at the cost of their own health and financial well-being. Today, the majority of those caring for another individual over age 50 are family caregivers.<sup>1</sup>

As the demand for caregiving grows with an aging population and as state and federal budgets are limited, it is imperative that we better support the informal caregiving population. Doing so can prevent a rise in more costly, formal care, such as in nursing homes, and also help families better balance the demands of work, family, and caregiving—and ultimately prevent health and mental health costs of the caregivers themselves.

This brief examines family characteristics of caregiving homes, the challenges they face, and potential intervention strategies to help ease the burden of caregiving.

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## Growing Need for Caregiving

There are roughly 61 million unpaid caregivers in the United States who provide care for the elderly or disabled adults and children at some point during the year.<sup>2</sup> Approximately two-thirds of family caregivers are female and providing care for an older relative.<sup>3</sup> Today the average caregiver is a 49-year-old woman caring for her elderly mother.

Family caregiving is influenced by the changing demographics of the American population. More women are in the workforce today (in 2010 women represented 47.6 percent of the workforce), which means they are juggling both job and family responsibilities.<sup>4</sup> In total, 58 percent of caregivers are currently working either full-time or part-time, and thus balancing work and caregiving.<sup>5</sup>

Caregiving demands are not going away. The population is aging, and with it the demand for care will likely rise. The average U.S. life expectancy today is 78 years, and by 2050 projections are for

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<sup>1</sup> L. Feinberg et al., “Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving” (Washington, DC: AARP Public Policy Institute, 2011), p. 4.

<sup>2</sup> Ibid.

<sup>3</sup> National Alliance for Caregiving and AARP. “Caregiving in the U.S.” (Bethesda, MD, and Washington, DC: AARP and NAC, 2009). [www.caregiving.org/data/caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/caregiving_in_the_US_2009_full_report.pdf)

<sup>4</sup> Bureau of Labor Statistics, Current Population Survey, “Table 3: Employment Status of the Civilian Noninstitutional Population by Age, Sex, and Race,” in *Annual Averages 2010* (Washington, DC: BLS, 2011).

<sup>5</sup> National Alliance for Caregiving and AARP, “Caregiving in the U.S.”

life expectancy reach 84.5 years.<sup>6</sup> By 2030, the number of U.S. adults aged 65 or older will more than double, to about 71 million.<sup>7</sup>

As the population ages, many older people will need care provided by younger people, but also, many older people will be able to help provide care for younger people. When discussing caregiving, we often think only the elderly needing assistance. However, older people also assume the caregiving role for children and disabled adults, when for example birth parents are unable to care for their children or parents are working long hours or in multiple jobs with fluctuating schedules. Other families have become intergenerational households owing to the recession and the foreclosure crisis.

In these and other cases, grandparents frequently contribute to caregiving.<sup>8</sup>

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Hiring caregivers for a loved one is unaffordable for many, averaging more than \$200 per day in caregiving costs. Thus, many family members assume the responsibilities themselves. The responsibilities of a caregiver include what those in the medical field call “activities of daily living” (ADLs). These can include preparing meals, feeding, bathing, dressing, as well as

dealing with finances, coordinating medical care, and providing transportation. However, they often provide a more important role, that of a loving and emotionally supportive person.

## Types of Caregiving Responsibilities

The majority of caregiving in the United States is for someone age 50 or older, and the majority of the care is related to health care needs. Some are acute conditions—a fall or a sudden change in health. Others are chronic conditions, including dementia and its related issues, diabetes, heart disease, and others. About 80 percent of older adults have one chronic condition, and 50 percent have at least two.<sup>9</sup>

Disabled adults are another group who frequently need care. Their care needs may stem from a cognitive disability, or, increasingly, they may include veterans with physical injuries. Many disabled adults are cared for by their own parents.

Caregiving for children encompasses two major groups: those who are chronically disabled and those whose parents are unable to care for them. Among family caregivers, 14 percent care for a special needs child under age 18; 55 percent of these caregivers are caring for their own children.<sup>10</sup>

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<sup>6</sup> N. Li and R.D. Lee, “Coherent Mortality Forecasts for a Group of Populations: An Extension of the Lee-Carter Method,” *Demography*, vol. 42, no. 3 (2005): 575-594.

<sup>7</sup> Centers for Disease Control, “Helping People To Live Long and Productive Lives and Enjoy a Good Quality Of Life.” (web page). <http://www.cdc.gov/chronicdisease/resources/publications/aag/aging.htm>

<sup>8</sup> Pew Research Center, “The Return of the Multigenerational Household” (Washington, DC: Pew Research, 2010). [www.pewsocialtrends.org/2010/03/18/the-return-of-the-multi-generational-family-household/](http://www.pewsocialtrends.org/2010/03/18/the-return-of-the-multi-generational-family-household/)

<sup>9</sup> CDC, “Helping People To Live Long and Productive Lives.”

<sup>10</sup> National Alliance for Caregiving and AARP. “Caregiving in the U.S.”

## Impacts on Families and the Workforce

Many studies find that caregiving can have negative effects on families' financial situation, retirement security, physical and emotional health, social well-being, and careers. A recent analysis finds that lifetime income-related losses for caregivers who leave the workforce are about \$115,900 in wages, \$137,980 in Social Security benefits, and \$50,000 from pension benefits.<sup>11</sup> A recent survey found that more than 40 percent of caregivers spend more than \$5,000 on caregiver expenses annually.<sup>12</sup> Caregivers for the elderly reported spending an average of more than 10 percent of their annual income on caregiving expenses in 2007.<sup>13</sup> In 2009, more than one in four family caregivers reported financial hardship due to caregiving.<sup>14</sup>

There is an impact on the workforce as well. Studies suggest that the cost of informal caregiving in terms of lost productivity to U.S. businesses is \$17.1 to \$33 billion annually. Costs reflect absenteeism (\$5.1 billion), shifts from full-time to part-time work (\$4.8 billion), replacing employees (\$6.6 billion), and workday adjustments (\$6.3 billion).<sup>15</sup>

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Caregivers also experience emotional distress. Caregiving has been associated with increased levels of depression and anxiety as well as higher use of psychoactive medications, poorer self-reported physical health, compromised immune function, and increased mortality.<sup>16</sup>

In addition, caregivers often must navigate a fragmented care system with multiple doctors, insurance complexities, and various health care provider policies for home care and other supports. In essence caregivers must become experts in medical care as well as chauffeurs.<sup>17</sup> Surveys find that the elderly accompanied by a family member account for 1.4 billion trips per year. Adult children provide 33 percent of these trips.<sup>18</sup>

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<sup>11</sup> MetLife Mature Market Institute, "The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents" (Westport, CT: MetLife Mature Market Institute, 2011).

<sup>12</sup> Caregiving.com, Usage and Attitude Survey.

<sup>13</sup> Interestingly, 10% is the same share that parents report spending on their young adults, aged 18-24. See Paul Wightman, Robert Schoeni, and K. Robinson, "Familial Financial Assistance to Young Adults," Prepared for the Annual Meetings of the Population Association of America, May 3, 2012, pp. 7-8.

<sup>14</sup> National Alliance for Caregiving, "Caregiving in the United States."

<sup>15</sup> MetLife Mature Market Institute, "The Met Life Study of Working Caregivers and Employer Health Care Costs: New Insights and Innovations for Reducing Health Care Costs for Employers" (Westport, CT: MetLife, 2010).

<sup>16</sup> MetLife Mature Market Institute, "The MetLife Study of Caregiving Costs," p. 6. See also, Feinberg et al., "Valuing the Invaluable," p. 4.

<sup>17</sup> Currently, Medicaid does provide transportation services. However, the coordination varies per state, and often the care needs are too immediate to wait for a service to respond.

<sup>18</sup> AARP Public Policy Institute analysis of the 2009 National Household Travel Survey Version 2.1

## Growing Resource and Policies Needs

Caregivers' selfless acts too often go unnoticed and unsupported. Recent estimates of the uncompensated cost of caregiving total approximately \$450 billion annually.<sup>19</sup> That is more than the annual costs of the Medicaid program, the primary payer for nursing home care and other long-term services and supports in the United States.<sup>20</sup>

In fiscal year 2010, more than one-half of the states reported increased demands for home and community-based services such as home-delivered meals and transportation. Since the economic downturn, local Agencies on Aging have received a 67 percent increase in requests for caregiver support services.

Given these rising costs, changing demographics, and caregiving strain, we must devise policies to more effectively preserve and promote informal caregiving, and support those who shoulder the financial responsibility of caring for those who cannot care for themselves.

## Policy Recommendations

The Affordable Care Act can help caregivers in its proposals to better coordinate medical care delivery, particularly through patient-centered medical homes. Having more coordinated care may help reduce the fragmentation in the health care system and resulting confusion among caregivers trying to navigate its complexities. Having a nurse or social worker to consult with could greatly increase caregiving quality and reduce physician or hospital visits.

The tax code is another source for policy initiatives. Currently, one of the only ways for caregivers to be reimbursed by the government for their services is to claim the person as their dependent. Caregivers in some circumstances may also claim medical expenses as deductions.

The federal government could also expand the National Family Caregiver Support Program to help reimburse costs of caregiving. The federal government could also provide funding for respite care to temporarily relieve caregivers of their duties, allowing them to maintain their caregiving responsibilities for an extended time.

Finally, in the context of broader Social Security reforms, consideration should be given to the possible crediting of caregiving quarters toward Social Security benefits, so that full-time, working-aged family caregivers are not forced to choose between the immediate needs of a family member and their own future financial security.

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<sup>19</sup> National Alliance for Caregiving, "Caregiving in the U.S."

<sup>20</sup> Ibid.