

THE SCOPE AND EFFECTS OF INFORMAL CAREGIVING



POLICY BACKGROUNDER

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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 Benefits of Life-Long Learning

Informal caregiving by family or friends of those who are suffering from acute or chronic health conditions is a vital link in the elder health care chain, and the need for such assistance will continue to grow as the population ages. Despite its importance, many caregivers struggle to provide care to their loved ones. Moreover, caregiving can have serious negative effects on caregivers' mental and physical health and on their short- and long-term finances, which can leave them entering their own retirements in poor health and with meager financial resources.

Progress has been made in establishing laws (e.g., the Family and Medical Leave Act) and programs (e.g., the National Family Caregiver Support Program¹) that can assist caregivers in fulfilling their roles and preserving their own physical and mental health and financial security. However, the economic downturn has taken a toll on state budgets that typically provide funding for assistance that alleviate both health effects and financial strain on caregivers and can help keep older adults in the home and out of far more costly nursing homes.

Like many other health and elder care issues that policymakers must grapple with today, the need to provide long-term care to older persons who suffer from chronic conditions is a relatively modern phenomenon, as explained in the AARP 2011 report:

Historically, everyday caring for ill family members was undertaken as an expected role by women within the privacy of the extended family and in a given community. As a consequence, it was largely ignored and rarely viewed as a public issue. Such family care was typically short term, because most people did not survive to old age...Today, average U.S. life expectancy is 78 years....Those who take on this unpaid role risk the stress, physical strain, competing demands, and financial hardship of caregiving, and thus are vulnerable themselves. Family caregiving is now viewed as an important public health concern.²

In 2009, about 42.1 million family caregivers in the United States provided care to an adult with limitations in daily activities at any given point in time

Today, informal caregivers—either relatives or friends—care for the vast majority of older adults with disabilities. The magnitude of informal caregiving services is such that, if such unpaid care were not available, the costs would overwhelm our health care system. Since the 1960s and 1970s, the trend of moving the elderly out of nursing homes and hospitals and back into home care settings has helped reduce the cost of nursing home care—and most older adults prefer to live in their own homes or the homes of their relatives. This trend also transferred caregiving back to families just as large numbers of women were

¹ The National Family Caregiver Support Program was established in 2000 and provides grants to states and territories based on their share of the population aged 70 or over to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. The Authorizing Legislation: Section 371 of the Older Americans Act of 1965, as amended.

² 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.

entering the workforce. With expanding life expectancy and the first of the baby boomers reaching age 65, the need for informal caregivers will continue to grow.

This backgrounder provides the foundation for the policy recommendations in the accompanying brief, “Policies to Better Support Informal Caregivers.” We begin with an explanation of the sometimes confusing array of methods and statistics used in measuring the demand and supply of informal caregiving in the United States. This is followed by an overview of the scope of informal caregiving today. Because caregivers are often family members juggling jobs and their own families, and because caregiving can be stressful and often underappreciated, not to mention unpaid, we look to the effects of caregiving on caregivers’ health and family income. Not all caregiving is burdensome, however. Therefore, we also examine the positive effects of caregiving. Finally, we look forward to future trends in informal caregiving.

A Word on Statistics and Definitions

This backgrounder cites statistics from several recent studies, some of which appear to provide conflicting data. Because caregivers can vary in regard to their relation to the person for whom they provide care (e.g., adult daughter, spouse, sibling, friend) and the person receiving care can vary from disabled children and adults to the elderly, the findings of studies may differ according to the respondent groups that researchers chose to include. Another variable among studies is how researchers choose to define “caregiving.” Some include only those tasks, and those caregivers who perform them, defined as activities of daily living (ADLs), which include dressing, bathing, toileting, and other similar activities. Others include instrumental activities of daily living (IADLs), which include less personally intensive activities than ADLs, such as taking the patient to a doctor or grocery shopping.

Caregivers fulfill a vital role by navigating in an increasingly fragmented health care system

National Health and Retirement Study (HRS) is the most widely used source for statistics on informal caregiving to the elderly. The HRS is funded by the National Institute on Aging, and conducted biannually by the University of Michigan. The HRS involves a nationally representative sample of adults over the age of 50 and provides information on income, work and health status, and whether respondents provide basic, personal care and/or financial assistance. Because HRS has been conducted since 1992, it provides useful, longitudinal data.

Several leading organizations use data from the HRS, with or without supplemental data from other sources. These groups include the AARP Public Policy Institute, the not-for-profit National Alliance for Caregiving, the not-for-profit Family Caregiver Alliance, the MetLife Mature Market Institute, and the Center for Long Term Care Research and Policy, New York Medical College. Over the past few years all of these groups have issued or contributed to reports discussing the impact of informal caregiving on the quality of life of elderly patients, on the economic and health effects on informal caregivers themselves, and on the impact on caregivers’ employers and the economy as a whole.

One point about the HRS is that it *understates* the magnitude of caregiving because it looks only at ADLs and financial assistance (at least \$500 of support to a parent in the last two years). It also only asks about care that respondents were giving to a parent, and not for example a spouse, grandparent, sibling, child with special needs, or other relative or friend. The respondents are also all at least age 50. As a recent MetLife study put it, “This means that the resulting data are quite conservative in that they do not reflect the entire spectrum of caregiving support, only that which focuses on an elderly parent(s).”³

Another important study, “Stress in America™: Our Health at Risk,” conducted by the American Psychological Association and released January 11, 2012, focused in part on stress among caregivers.⁴ Unlike the HRS, the Stress in America™ survey included respondents from four generations: Millennials (18–32-year-olds), Generation X (33–46-year-olds), Boomers (47–65-year-olds) and Matures (66 years and older). In this study, the average age of caregivers was 49.

The Scope of Caregiving in the United States

In 1994, researchers using HRS data reported that 3 percent of men and 9 percent of women provided help with basic care to parents. By 2008, these percentages had increased to 17 percent of men and 28 percent of women.⁵ According to a 2011 report from AARP’s Public Policy Institute,

In 2009, about 42.1 million family caregivers in the United States provided care to an adult with limitations in daily activities at any given point in time, and about 61.6 million provided care at some time during the year. The estimated economic value of their unpaid contributions was approximately \$450 billion in 2009,^[6] up from an estimated \$375 billion in 2007. The estimates do not include caregivers or care recipients under age 18; nor do they include caregivers who provide assistance to adults who have chronic health conditions or disabilities but do not provide assistance with any activities of daily living (ADLs) (such as bathing or dressing) or instrumental activities of daily living (IADLs) (such as managing medications or finances).⁷

To understand the scope of this outlay, the estimated \$450 billion is about 3.2 percent of the U.S. gross domestic product (\$14.1 trillion in 2009).⁸ In addition, it is:

- More than total Medicaid spending in 2009, including both federal and state contributions for both health care and Long-Term Support Services (LTSS) (\$361 billion).
- Nearly four times Medicaid LTSS spending in 2009 (\$119 billion).

³ MetLife Mature Market Institute, “The MetLife Study of Caregiving Costs to Working Caregivers, Double Jeopardy for Baby Boomers Caring for Their Parents” (New York: MetLife Mature Market Institute, June 2011), p. 6.

⁴ This section of the report focused primarily on 300 caregivers among a larger study of approximately 1,200 who responded to the question, “Do you currently care for an aging or chronically ill family member?”

⁵ MetLife Mature Market Institute, “The MetLife Study,” p. 7

⁶ This number is based on 42.1 million caregivers age 18 or older providing an average of 18.4 hours of care per week to care recipients age 18 or older at an average value of \$11.16 per hour.

⁷ Feinberg, “Valuing the Invaluable,” p. 1.

⁸ *Ibid.*, p. 3.

- More than twice total paid LTSS, regardless of payer source (\$203 billion in 2009).⁹

Along with the significant outlays are significant numbers of older people served. Fully two out of three (66 percent) older people with disabilities who receive LTSS (Long-Term Support Services) at home get all their care exclusively from their family caregivers, mostly wives and adult daughters. Another one-fourth (26 percent) receives some combination of family care and paid help. Only 9 percent receive paid help alone.¹⁰

Caregivers and the Care They Provide

According to the AARP Public Policy Institute, the typical U.S. caregiver is “a 49-year-old woman who works outside the home and spends nearly 20 hours per week providing unpaid care to her mother for nearly five years. Almost two-thirds of family caregivers are female (65 percent). More than eight in ten are caring for a relative or friend age 50 or older.”¹¹ Persons who receive care include those who suffer from “acute” conditions, such as a broken hip, or chronic conditions, such as diabetes or dementia.

Activities that compose “caregiving” range from running the occasional errand for older family members or friends to supporting ADLs. Some who are providing care, particularly if it is occasional and does not involve ADLs, do not consider themselves caregivers.

As additional time and effort in caring for others progresses, so too does the potential for caregivers to experience health effects and psychosocial and behavioral impacts, such as depression or chronic disease.¹² A survey published in 2009 by the National Association of Caregiving and AARP¹³ indicates that the self-reported health of caregivers declines the longer they provide care. In this study, “31 percent of adult caregivers report stress, anxiety, or depression; 70 percent report making work accommodations due to caregiving; and 53 percent say that they lose time with friends and family.”¹⁴ The impact on the health of caregivers is particularly severe for those who are caring for those with complex chronic health conditions and both functional and cognitive impairments.¹⁵

Caregivers report higher rates of cholesterol, high blood pressure, overweight/obesity, and depression than national averages

Trends in medical practice, which seek to minimize the length of hospital stays and provide for outpatient care, have resulted in cost savings for hospitals and consumers alike. However, shortened

⁹ Ibid., p. 2.

¹⁰ Ibid., p. 8.

¹¹ Ibid., p.1

¹² MetLife Mature Market Institute, “The MetLife Study of Caregiving Costs,” p. 15.

¹³ 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

¹⁴ MetLife Mature Market Institute, “The MetLife Study of Caregiving Costs,” p. 14.

¹⁵ Feinberg, “Valuing the Invaluable,” p. 5.

hospital stays also often mean that family members or other informal caregivers are more often dealing with long-term, complex health problems. As a recent review of caregiving found, “Family caregivers are more frequently called upon to use daunting and complex equipment at home. They also deal with extensive coordination of care, including symptom management, disability, mobility, and dressings. In the face of these increasing challenges and responsibilities, caregivers often feel tired, isolated, and overwhelmed, because they lack support, training, information and a sympathetic ear.”¹⁶

Lack of adequate preparation can lead to high levels of caregiver stress, which in turn can lead to nursing home admissions that might not otherwise have occurred. Rehospitalization or nursing home placement soon after patient discharge is often due to an absence of care coordination, poor communication from health care providers, and a lack of follow-up care and supportive services when caregivers are asked to deliver care that they have not been adequately trained or prepared to deliver.¹⁷

In addition to providing care within the home, caregivers fulfill a vital role by navigating in an increasingly fragmented health care system—an act that is, in itself, a stressful effort. The proportion of older adults experiencing continuity of care between doctors’ offices and admission to hospitals decreased substantially between 1996 and 2006. By 2006, only four in ten older adults received care from any physician they had seen at least once in a doctor’s office in the prior year.¹⁸ On the other hand, according to the AARP Public Policy Institute, family members or other informal caregivers “generally view chronic illness and disability from the perspective of the ‘whole person,’ not as separate, discrete services or treatments,”¹⁹ an important factor in the delivery of appropriate care.

Health Effects of Caregiving on Caregivers

According to an article in the *Journal of the American Medical Association*, highly strained family caregivers are at risk of premature death.²⁰ The role of caregiving “fits the formula for chronic stress so well that it is used as a model for studying the health effects of chronic stress...”²¹

It creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance.²²

¹⁶ J. W. Lim and B. Zebrack, “Caring for Family Members with Chronic Illness: a Critical Review of Caregiver Literature,” *Health and Quality of Life Outcomes*, vol. 2 (2004). www.hqlo.com/content/2/1/50.

¹⁷ Feinberg, “Valuing the Invaluable,” p. 9.

¹⁸ *Ibid.*

¹⁹ *Ibid.*, p. 4.

²⁰ R. Schulz and S. R. Beach, “Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study,” *Journal of the American Medical Association*, vol. 15 (1999): 2215-2219.

²¹ R. Schulz and P.R. Sherwood, “Physical and Mental Health Effects of Family Caregiving,” *Journal of Social Work Education*, vol. 44, no. 3 (Fall 2008); Supplement.

²² Schulz and Sherwood, “Physical and Mental Health Effects of Family Caregiving,” p. 105.

As the Stress in America™ survey reports:

Caregivers are more likely than those in the general population to report doing a poor/fair job in preventing themselves from experiencing stress (55 percent vs. 44 percent) and fully recovering after it occurs (39 percent vs. 31 percent).

Caregivers are not only more likely to report stress, but also report it at a higher level than is reported by the general public. On a scale of 1 to 10 where 1 is little or no stress and 10 is a great deal of stress, the mean level of stress reported by caregivers was 6.5 as compared to 5.2 by the general public. In addition, the study found that caregivers are more likely than the general public to say their stress has increased in the past five years (59 percent vs. 44 percent).²³

The most stressful situations typically involve providing care to loved ones suffering from Alzheimer’s disease or other dementing conditions. As research R. Schulz and S. R. Beach write in a recent report, “People with dementia typically require more supervision, are less likely to express gratitude for the help they receive, and are more likely to be depressed. All of these factors have been linked to negative caregiver outcomes.”²⁴ Caring for loved ones with dementing illness is associated with depression, physical health problems, sleep problems, social isolation, mortality, and a greater risk of the caregiver’s developing dementia.²⁵

The most stressful caregiving involves providing care to loved ones suffering from Alzheimer’s disease.

Studies have shown that the effects of stress can be moderated to a certain extent by age, socioeconomic status, and the availability of informal support. Younger caregivers, those with higher socioeconomic status (that is, education, income, and occupational status), and those with greater support networks are less at risk for negative psychological and physical health effects.²⁶ One exception to the tendency for age to moderate the negative effects is when older individuals are themselves caregivers, often to a spouse or friend. This group reports more stress and poorer physical health than their peers.²⁷ In addition, older adults in caregiver roles may be particularly vulnerable because caregiving demands can compromise their immune response systems and the stress associated with caregiving can exacerbate existing health conditions.²⁸

Researchers have found that depending on the duration and type as well as other stressors such as finances, caregiving can also contribute to poorer physical health. Caregivers may neglect their own

²³ American Psychological Association, “Stress in America™: Our Health at Risk” Washington, DC: APA, January 11, 2012), p.7.

²⁴ Schulz and Sherwood, “Physical and Mental Health Effects of Family Caregiving,” p. 108.

²⁵ Feinberg, “Valuing the Invaluable,” p. 8.

²⁶ Schulz and Sherwood, “Physical and Mental Health Effects of Family Caregiving,” p. 106.

²⁷ APA, “Stress in America,” p. 5.

²⁸ From M. Navale-Waliser et al., “When the Caregiver Needs Care: The Plight of Vulnerable Caregivers,” American Journal of Public Health, vol. 92 (2002): 409-413.

health care appointments or eat poorly. They can also become socially isolated.²⁹ The Stress in America™ survey results indicate that caregivers report higher rates of cholesterol, high blood pressure, overweight/obesity, and depression than national averages.³⁰ Compared with the general population:

Caregivers report having a chronic illness (82 percent vs. 61 percent), report that their health is fair or poor (34 percent vs. 20 percent) ..., and report physical (94 percent vs. 76 percent) and non-physical (91 percent vs. 71 percent) symptoms of stress In addition, caregivers ... are almost three times more likely than noncaregiver respondents to get sick five times a year or more (17 percent vs. 6 percent).³¹

In the HRS study sample, regardless of the caregiver's gender, workers who provide support for ADLs reported that their health was only fair or poor (14–17 percent). This compares with 11–14 percent of workers who did not provide any basic personal care.³²

Economic Effects of Caregiving

Caregiving has significant effects on the personal finances and long-term financial security of caregivers. Employers of caregivers as well as the economy as a whole also incur costs from informal caregiving. These costs include loss of wages, pensions, and Social Security benefits when caregivers

The cost impact of caregiving on the individual female caregiver in terms of lost wages and Social Security benefits equals \$324,044.

quit their jobs before retirement age. They also include greater employer-paid medical care costs for caregivers who are still employed but who are suffering from declining physical and emotional health as a consequence of their caregiving.

According to the HRS, well over one-half (58 percent) of caregivers works full- or part-time while providing care. Nearly three-quarters (74 percent) held a job during some of the time when they were also working as caregivers. Thus, the stress of juggling caregiving responsibilities with work and other family obligations

is an ongoing issue that can have a significant impact on caregivers who are employed. As a MetLife reported noted, “For all working caregivers, it is not unusual also to report missed opportunities for promotions, business travel, relocation, and education as workplace effects of providing care.”³³

According to the AARP:

²⁹ Schulz and Sherwood, “Physical and Mental Health Effects of Family Caregiving,” p. 106.

³⁰ APA, “Stress in America,” p.7.

³¹ APA, “Stress in America,” pp. 7-8.

³² MetLife Mature Market Institute, “The MetLife Study of Caregiving Costs,” p. 16.

³³ From MetLife Mature Market Institute, “The MetLife Study of Caregiving Costs,” p.12; M.B. Lilly, A. Laport, and P.C. Coyte, “Labor Market Work and Home Care’s Unpaid Caregivers: A Systematic Review of Labor Force Participation Rates, Predictors of Labor Market Withdrawal, and Hours of Work,” *Milbank Quarterly*, vol. 84, no 4 (2007): 641-690.

Nearly seven in ten (69 percent) caregivers report making work accommodations because of caregiving. These adjustments including arriving late/leaving early or taking time off, cutting back on work hours, changing jobs, or stopping work entirely. Family caregivers with the most intense level of caregiving (those who provide 21+ hours of care each week), those with high burden of care, or those who live with their care recipient are especially likely to report having to make workplace accommodations.³⁴

The economic downturn has increased the pressure on caregivers. One-half of caregivers reported that they were less willing to take time off from work to provide care, and one-third said they were faced with having to work more hours or get an additional job to cover caregiving costs. An online survey found that one-third of employed caregivers said that the recession caused them to quit their job, retire early, reduce work hours, or take a leave of absence.³⁵

The 2011 MetLife Study examines in detail the financial costs to both female and male caregivers.

For women, the total individual amount of lost wages due to leaving the labor force early because of caregiving responsibilities equals \$142,693. The estimated impact of caregiving on lost Social Security benefits is \$131,351. A very conservative estimated impact on pensions is approximately \$50,000. Thus in total, the cost impact of caregiving on the individual female caregiver in terms of lost wages and Social Security benefits equals \$324,044.

For men, the total individual amount of lost wages due to leaving the labor force early because of caregiving responsibilities equals \$89,107. The estimated impact of caregiving on lost Social Security benefits is \$144,609. Adding in a conservative estimate of the impact on pensions at \$50,000, the total impact equals \$283,716 for men.³⁶

Using these figures, the authors concluded that the average cost of lost wages, Social Security benefits, and pension benefits for both men and women is \$303,880. They further concluded that, “When this \$303,880 is multiplied by the 9.7 million people 50+ caring for their parents, the amount lost is ... nearly \$3 trillion.”³⁷

Caregivers with the lowest incomes report spending more than 20 percent of their annual income on out-of-pocket caregiving expenses

Out-of-Pocket Expenses

³⁴ Feinberg, “Valuing the Invaluable,” p. 6

³⁵ Ibid., p. 7.

³⁶ MetLife Mature Market Institute, “The MetLife Study of Caregiving Costs,” p. 2.

³⁷ Ibid. p. 15

Family and individual caregivers' finances are also affected by out-of-pocket expenses, which can be considerable, especially for lower-income caregivers and families. According to the AARP, in 2007, "caregivers to persons age 50 and older reported spending an average of more than 10 percent of their annual income on caregiving expenses, or an average of \$5,531 out-of-pocket."³⁸ Moreover, caregivers with the lowest incomes (less than \$25,000) have reported spending more than 20 percent of their annual income on out-of-pocket caregiving expenses. The report adds that caregivers who provide care from long-distance averaged annual out-of-pocket expense of \$8,728.³⁹

The immediate impact of such out-of-pocket expenditures—especially on lower-income caregivers or caregivers who have had to reduce their hours of work or leave their jobs entirely—are significant; however, data regarding how caregivers pay for these extra expenses suggest that they will also have a negative long-term effect on caregivers' financial security:

Employers lose an estimated \$33.6 billion in productivity annually from costs associated with employees who are also full-time caregivers

One-third of caregivers (34 percent) indicated that they used their savings to pay for these expenses, while nearly one-quarter (23 percent) paid for them by cutting back spending on their own preventive health or dental care. Finally, nearly four in ten (38 percent), stated that in order to pay these expenses, they had reduced or stopped saving for their own future.⁴⁰

Economic Effects on Employers

U.S. businesses lose an estimated average of \$2,110 per full-time caregiver annually from costs associated with replacing employees, absenteeism, workday distractions, supervisory time, and reductions in hours as formerly full-time workers move to part-time work. Collectively, employers lose an estimated \$33.6 billion in productivity annually from costs associated with employees who are also full-time caregivers.⁴¹

Another financial effect is increased costs for employee health care. In one study, employed caregivers of older relatives cost their employers 8 percent more in regard to health care than employees who did not meet the HRS definition of "caregiver"—in aggregate, a total potential cost of \$13.4 billion more per year. As noted above, the health impacts on caregivers are broad. Employees age 50 and above who were providing care for an older

³⁸ Feinberg, "Valuing the Invaluable," p. 6

³⁹ Ibid.

⁴⁰ Ibid.

⁴¹ Ibid, p. 7.

relative were significantly more likely to report depression, diabetes, hypertension, or pulmonary disease than noncaregivers of the same age. In addition, caregivers of people who suffer from dementia were found to be “more likely to have an emergency department visit or hospitalization in the previous six months if they were depressed or were taking care of individuals with heavy care needs.”⁴² It thus appears that the challenge of eldercare responsibilities in the workplace is an important factor in health care costs of businesses.⁴³

Positive Effects

Despite the negative effects that can result from the stress that caregiving can cause, researchers have also found that many informal caregivers “find it a source of deep satisfaction and meaning.”⁴⁴ Further:

In studies with large population-based samples, about one-third of caregivers report neither strain nor negative health effects. Particularly in the early stages of caregiving, negative effects may not occur. Even when caregiving demands become more intense and result in high levels of distress and depression, caregivers often cite positive aspects of the experience. They report that caregiving makes them feel good about themselves and as if they are needed, gives meaning to their lives, enables them to learn new skills, and strengthens their relationships with others....

...After controlling for baseline health status, Brown and colleagues found that individuals who provided IADLs ...to friends, relatives, or neighbors and people who provided emotional support to their spouses had lower five-year mortality rates than individuals who didn't help others or didn't support their spouses.⁴⁵

In addition, the negative health effects that can occur from the stress of caregiving can be alleviated when caregivers' receive additional support in their duties from family members:

For example, caregivers who feel adequately supported report significantly lower stress levels than those who do not (5.9 vs. 6.9); are less likely to report anger/irritability (48 percent vs. 69 percent), feeling depressed or sad (39 percent vs. 55 percent), feeling lonely and isolated (24 percent vs. 47 percent) and less likely to report that, when they are feeling stressed, that they have isolated themselves from others (24 percent vs. 42 percent) than caregivers who do not feel supported.⁴⁶

⁴² Ibid, p. 8.

⁴³ Ibid.

⁴⁴ Feinberg, “Valuing the Invaluable,” p. 1.

⁴⁵ Schulz and Sherwood, “Physical and Mental Health Effects of Family Caregiving,” p. 109.

⁴⁶ APA, “Stress in America,” pp. 10-11

Strategies to Mitigate Stress

Respite Care and Other Supports

Evidence on the health effects of caregiving gathered over the last two decades has helped convince policymakers that caregiving is a major public health issue.⁴⁷ Thus, programs such as respite care are designed to deliver such support as well. The Lifespan Respite Care Program, which was established as a result of legislation passed in 2005 and is managed under the federal Administration on Aging,⁴⁸ brings “together Federal, state and local resources and funding streams to help support, expand, and streamline the delivery of planned and emergency respite services....for family caregivers of children or adults of all ages with special needs.”⁴⁹

In addition to respite care that is carried out within home settings, respite care can also involve “adult day care,” where older adults can spend time out of the home in a sheltered setting where they can enjoy the added benefit of socializing with others from their community while their caregivers enjoy a break from their duties.

A hallmark of the federal government’s approach to providing assistance to aging adults, others in need of care, and the caregivers who provide it has been to provide grants to state agencies.

A hallmark of the federal government’s approach to providing assistance to aging adults, others in need of care, and the caregivers who provide it has been to provide grants to state agencies (State Units on Aging), which, in partnership with Area Agencies on Aging and with collaboration with community-based service providers and other stakeholders, provide funding to meet local caregiving needs.⁵⁰ For example, the National Family Caregiver Support Program (OAA Title III-E),⁵¹ which was established in 2000, provides grants to states and territories, based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.

Among the many services and other innovations in government-provided assistance to caregivers offered under the Administration on Aging’s Community Living Program (CLP),

⁴⁷ Schulz and Sherwood, “Physical and Mental Health Effects of Family Caregiving,” p.105

⁴⁸ The Administration on Aging (AoA) was created under the Older Americans Act, which was passed by Congress in 1965 in response to concern by policymakers about a lack of community social services for older persons, to administer the newly created grant programs and to serve as the federal focal point on matters concerning older persons. Authorizing Legislation: Title XXIX of the Public Health Service Act (42 U.S.C. 201)

⁴⁹ http://www.aoa.gov/AOARoot/AoA_Programs/HCLTC/LRCP/index.aspx

⁵⁰ U.S. Department of Health and Human Services, Administration on Aging, “Community Living Programs (CLP).” Fact Sheet (Washington, DC: HHS, n.d.).

⁵¹ Authorizing Legislation: Section 371 of the Older Americans Act of 1965, as amended.

About one-third of companies in 2005 with 100 or more employees offered elder care resource and referral services in those years.

formerly known as Nursing Home Diversion (which provides grants that allow persons who are at risk of nursing home admission to remain at home and receive home-based care) is the Cash and Counseling model. Cash and Counseling, which provides a monthly allowance to recipients of Medicaid personal care services or home and community based services, has been operated as a

demonstration initiative in 15 states. Evaluations of its impact on helping to alleviate financial, emotional, and health burdens have been promising:

Evaluations of the demonstration programs...suggest benefits for family caregivers who participated in the program; including lowered levels of physical, emotional, and financial strain; improved feelings of satisfaction with life; fewer burdens on privacy, social life, and job performance; and increased feelings of satisfaction with care recipients' care arrangements....

The Cash and Counseling model is important in the caregiving policy debate because it allows consumers (or care recipients) to make choices about their care, including the ability to hire relatives and loved ones to provide their caregiving needs, which would help to ease caregiver burden. Such approaches provide a promising flexible alternative to traditional community-based long-term care that assists not only the care recipient, but also the loved ones who provide their care.⁵²

Unfortunately, in 2010, 31 states cut non-Medicaid aging and disability services programs, and an estimated 28 states were expecting to reduce home care-based services programs in FY 2011.⁵³

Workplace Strategies

Although workplace policies are in place to help workers balance work and family demands, they are not widely used, and more should be done to expand flexibility at work for caregivers of all ages. According to a 2005 report from the Families and Work Institute, about one-third of companies in 2005 with 100 or more employees offered elder care resource and referral services in those years (up from one-fourth in 1997). However, only 9 percent offered long-term care insurance for family members and only 5 percent made direct financial contributions to elder care programs in the communities where they operate.

⁵² D. L. Elmore and R. C. Talley, "Family Caregiving and U.S. Federal Policy." In *Aging Families and Caregiving*, edited by S. H. Qualls and S. H. Zarit (Hoboken, NJ: John Wiley, 2009), p. 214.

⁵³ Feinberg, "Valuing the Invaluable," p. 10.

Among companies offering any form of elder care assistance, about one in five thinks the costs outweigh the benefits. Sixty percent see the programs as cost-neutral, and one in five thinks they offer a positive return on the investment. The share dissatisfied with returns is higher than in programs offering child care assistance but in line with the share who think flexible work arrangements and family leave policies cost more than they return. More broadly, as the report notes, “although many employers (63 percent) report that supervisors are encouraged to be supportive of employees with family needs by finding solutions that work for both the employee and the employer, only 27 percent report that the organization makes a real and ongoing effort to inform employees of available assistance for managing work and family responsibilities.”⁵⁴

Other policies that can help family members balance work and caregiving include flex time and being able to work from home, yet fewer than 5 percent of employers with more than 100 employees offer these perks to workers. Only one in five allows a sabbatical for six months with return to a comparable job. In contrast, about two-thirds (62 percent) allow workers to take time off for personal needs without loss of pay, and about one-half (48 percent) offer extended care breaks to care for family members. Smaller employers—with between 50 and 99 employees—are typically more flexible in their family support policies.

Among companies offering any form of elder care assistance, 60 percent see the programs as cost-neutral.

Being able to work and balance caregiving demands could go a long way to alleviating stress by both reducing social isolation, having an outlet for interaction, and not having to worry about whether “the boss” is upset. Being able to continue working while taking time to care for a family member can also help prevent caregivers from slipping into poverty or finding themselves unable to save for retirement. For employers, family-friendly policies are increasingly seen as strategic tools for recruiting, retaining, workers and improving their productivity on the job, and as the Families and Work Institute report puts it, for “making work ‘work’ for both employers and employees.”

Additional Research into Caregiver Stress and the Efficacy of Interventions

Despite the vast amount of research available on caregiving and its effects, many of the results potentially under- or overstate the outcomes or issues in question. Much of the

⁵⁴ Families and Work Institute, “2005 National Study of Employers” (New York: Families and Work Institute, 2005).

research is based on cross-sectional analyses of relatively small opportunity samples. Studies may also fail to control for basic demographic characteristics, such as levels of education or socioeconomic levels, which have been shown to affect health, or even initial health status.⁵⁵ This can be the case even in large, longitudinal, or case-control studies. The result is that any differences identified between caregivers and others may not be the direct result of caregiving, but instead some underlying, preexisting issues or demographic characteristics that also influence health, stress, or other outcomes. Those with low socioeconomic status, for example, are both more likely to be caregivers and at risk for poor health. Documented higher rates of illness among spouse caregivers may spring from “assortative” mating, in which we seek out mates with similar backgrounds and upbringings. The higher rates may also arise from shared diets, preferences, or health habits between spouses.⁵⁶

Owing to research design shortcomings, many of the results potentially under- or overstate the outcomes or issues in question.

Also, although providing intensive caregiving, such as providing assistance with basic ADLs for 20 or more hours a week, is associated with the likelihood and severity of negative health effects in caregivers, evidence suggests that other factors, such as the level of patient suffering, may contribute just as much to a health decline in the caregiver. Therefore, it is important to disentangle the effects of helping from other aspects of caregiving.⁵⁷

Researchers Steven Zarit and Elia Femia suggested in a 2008 article that some clinical trials had failed to provide insights into the true efficacy of interventions because they failed to consider the “dosage” of interventions such as respite care that are necessary to show therapeutic value. In many instances, the amount of care or respite provided is minimal, which is a likely reason for the apparent “failure” of services. Zarit and Femia estimated the true dose needed to have an effect, in the case of respite care, the ailing parent or relative would need to attend adult day services at least twice a week for three months for the caregiver to see any improvement. “Dosage,” the researchers, argue “should not be left to guesswork, nor should it be determined, as has sometimes happened, by economic considerations that limit treatment without regard to the amount of help that could actually make a difference. Instead, the amount of treatment needed to make a therapeutic difference should be determined as part of the treatment process.”⁵⁸

⁵⁵ Feinberg, “Valuing the Invaluable,” p. 10.

⁵⁶ Schulz and Sherwood, “Physical and Mental Health Effects of Family Caregiving,” pp. 109-110.

⁵⁷ *Ibid.*, pp. 110-111.

⁵⁸ S. Zarit and E. Femia, “Behavioral and Psychosocial Interventions for Family Caregivers,” *Journal of Social Work Education*, vol. 44, no. 3 (Fall 2008); Supplement.

In other cases, trials of psychological interventions that use scripted protocols, rather than the flexibility to address the multidimensional nature of the factors that can affect caregivers' levels of stress, fail to provide the information necessary to craft interventions that can effectively address caregivers' real-world needs.⁵⁹

Future Trends

The role that informal caregivers play in providing care to older residents who need assistance and helping to contain the cost of long-term care is already substantial, as are, unfortunately, some of the negative financial, physical, and psychological effects on the caregivers themselves. Further, as the MetLife study notes, the number of persons over

“The nation is bracing for the impact of providing health care services to these 72 million aging adults, but what may be lacking is concern about the impact on caregivers.”

the age of 50 who are currently providing care to their parents (approximately 9.7 million)⁶⁰ “suggests that family caregivers are themselves aging and yet are providing care at a time when they also need to plan and save for their own retirement. These factors are especially important as workers emerge from the economic recession in the U.S. and its impact on their future financial security.”⁶¹

As we brace for a rapidly aging population, we risk overlooking this important group. As the American Psychological Association states, “The nation is bracing for the impact of providing health care services to these 72 million adults, *but what may be lacking is concern about the impact on caregivers.*”⁶² (Emphasis ours.)

Moreover, the trend away from nursing home care and toward home-based care, which most persons with chronic conditions and disabilities prefer, has come at a time when families are smaller and more dispersed than they used to be and as women continue to play an important role in the workforce. Over the past decades, the American family has not only become more like a beanpole—tall and narrow with several generations alive but with fewer children in each generation—but it has become more fractured and “blended.”

⁵⁹ Ibid., pp. 50-51

⁶⁰ MetLife Mature Market Institute, “The MetLife Study of Caregiving Costs”: “The figure, 9.7 million parental caregivers, is derived by multiplying the percentage of the HRS survey respondents who provided basic and/or financial help to a parent, by the 2008 Census population estimates for their respective age groups and the estimated proportion of adults having a living parent.”

⁶¹ MetLife Mature Market Institute, “The MetLife Study of Caregiving Costs,” p. 4.

⁶² “Stress in America: Our Health at Risk,” American Psychological Association, Released January 11, 2012. P. 5.

The rise of divorce and more recently of cohabitation before marriage (or instead of marriage) means that many more families have multiple sets of grandparents, and multiple variations of step-siblings, step-children, and step-parents. As sociologist of the family Andrew Cherlin noted, step-children are much less likely to provide support to nonbiological parents. That might change going forward, but it is not yet the case.”⁶³

On the other hand, the greater contact and dependency among Millennials on their parents well into their twenties and even early thirties may engender stronger obligation later in life. Increasingly, women are opting not have children or are unable to have children. Currently, one in five women over age 40 are childless. Given that adult children typically provide caregiving, the trends suggest that we will need more nonfamily caregivers in the future. And lest one believe that “friends are the new family,” according to Pew Research, only 39 percent of respondents said they’d help a best friend with serious problem. Clearly we must plan for this future of potentially diminished family caregivers because currently, without the unpaid contributions of these family caregivers, the health and the long-term support services system would be overwhelmed.⁶⁴

Policy Recommendations

With tight federal and state budgets, it is important to consider how we can assist informal caregivers in order to forestall a substantial increase in the need for paid, formal caregivers, rehospitalizations, and avoidable nursing home admissions. Policies that would help reduce the long-term need for caregiving assistance include investments in cures and treatments for the medical conditions that most frequently exhaust family caregivers, such as Alzheimer’s disease and other dementias, urinary incontinence, and broken hips. Additional research into the therapeutic levels required for interventions to prove effective should also be undertaken.

In the near term, the best investments are those that support the ability of family and other informal caregivers to shoulder their responsibilities. These could include:

- Improved short-term disability leave from work to allow a caregiver time off without having to give up a job (or retirement program). The Family and Medical Leave Act should be strengthened to provide paid leave for those who must take on caregiving responsibilities.
- Training programs, both in person and online, tailored to specific caregiver situations.

⁶³ Personal communication, September 13, 2012.

⁶⁴ Feinberg, “Valuing the Invaluable,” p. 10.

- Peer support programs, modeled on Alcoholics Anonymous or Weight Watchers, for example, to provide emotional support, resources, and a place to discuss challenges in a confidential setting.
- Increased availability of skilled nursing staff who can provide hands-on training and assistance to caregivers who are faced with providing complex home care tasks, especially in conjunction with newly discharged patients, to reduce rehospitalizations and/or avoidable nursing home placement.

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. Making nursing staff or social workers more available for consultation could greatly the quality of caregiving and reduce physician or hospital visits.

The tax code is another source of 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. Extending the Earned Income Tax Credit so that it could alleviate some of the out-of-pocket and other financial burdens on lower-income families is another avenue that should be explored.

The federal government should also consider expanding the National Family Caregiver Support Program to help reimburse costs of caregiving through the Cash and Counseling initiative, which is not yet available in all states. Additional funding to the states through the Lifespan Respite Care Program for to pay for respite care would also assist caregivers by helping to alleviate the stress and isolation that intensive caregiving duties can cause, allowing them to maintain their caregiving responsibilities for an extended time with less negative effects on their health.

Finally, in the context of broader Social Security reforms, considerations 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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