

Families and Elder Care in the Twenty-First Century

Ann Bookman and Delia Kimbrel

Summary

Although most Americans know that the U.S. population is aging, they are far less informed about the reality of providing elders with personal care, health care, and social support. Families—particularly women—have always been critical in providing elder care, but the entry of so many women into the paid labor force has made elder care increasingly difficult.

Ann Bookman and Delia Kimbrel show how changes in both work and family life are complicating families' efforts to care for elderly relatives. Because almost 60 percent of elder caregivers today are employed, many forms of caregiving must now be “outsourced” to nonfamily members. And because elders are widely diverse by race and socioeconomic status, their families attach differing cultural meanings to care and have widely different resources with which to accomplish their care goals. Although the poorest elders have access to some subsidized services, and the wealthiest can pay for services, many middle-class families cannot afford services that allow elders to age in their homes and avoid even more costly institutional care.

Six key groups—health care providers, nongovernmental community-based service providers, employers, government, families, and elders themselves—are engaged in elder care, but their efforts are often fragmented and uncoordinated. All six groups must be able to work in concert and to receive the resources they need. Both employer and government policies must be improved. Although large businesses have taken up the elder care challenge, most small and mid-sized firms still do not offer flexible work arrangements. Social Security and Medicare have provided critical support to families caring for elders, yet both face significant financial shortfalls. The Older American Act and the National Family Caregiver Support Program have broadened access to elder services, but need updating to address the needs of today's employed caregivers and elders who want to “age in place.” And just over half of the nation's workforce is eligible for the unpaid leave benefits provided by the Family and Medical Leave Act.

The authors close by reflecting on the need for a coordinated, cross-sector movement to create an “aging-friendly” society in the United States—a society that values well-being across the life span and supports citizens from diverse cultures and income levels as they age.

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For most of the nation's history, caring for the elderly was a family affair carried out largely by women in the home. As the twenty-first century unfolds, however, elder care in the United States is an increasingly complex enterprise, with much personal care "outsourced" to paid nonfamily caregivers. Today elder care is a multisector undertaking with six key stakeholder groups—health care providers, nongovernmental community-based service agencies, employers, government, families, and elders themselves. The six groups, however, often work separately, or even at cross-purposes. They must be better integrated and resourced to ensure that seniors can age with dignity, families can receive appropriate supports, and society can manage the costs associated with geriatric health care and elder economic security.

In this article we examine the changing demographics of elders and families; what it means to engage in care work of an elderly parent or relative; how caregiving varies by race, gender, and socioeconomic status; and institutional responses to the challenges of caregiving from employers and the government. We close with reflections on the need for a coordinated, cross-sector movement to create an "aging-friendly" society in the United States—a society that values well-being across the life course and seeks multi-generational solutions.

Changing Demographics

With the numbers of older Americans rapidly growing ever larger, the landscape of elder care in the United States is changing. During the past century, the population of Americans aged sixty-five and older increased eleven-fold.¹ According to the 2010 census, 13 percent of the population, or 40.3 million

individuals, were sixty-five or older.² The population share of those aged eighty-five and older, sometimes called the "oldest old," was 1.1 percent. By 2030 approximately 80 million Americans, or 20 percent of the population, are projected to be sixty-five or older, and 2.3 percent of the population will be eighty-five and older.³

In addition to its increasing numbers over the coming decades, the elderly population will change in a variety of ways—more people will live longer and healthier lives, the number of older males will grow, and the group's racial and ethnic diversity will increase.⁴ But not all trends are positive. Although the poverty rate among the elderly fell from 25 percent in 1970 to 13 percent in 1992, as the real median income of both males and females increased,⁵ in 2009, approximately 12.9 percent of people 65 and older still had incomes at the poverty level.⁶ The Great Recession that began in 2007 eroded the economic status of moderate-income and middle-class elders, many of whom saw their pensions and 401(k)s decrease, the value of their homes decline, and their other financial investments lose value.⁷

Clearly these changes in the nation's elderly population will present challenges to family members who help provide elder care. And other national demographic shifts—delayed marriage and childbearing for young adults, decreased family size, and changes in family composition and structure—are complicating that challenge. Increased longevity among elders not only extends the years of caregiving by their adult children but may require their grandchildren to become caregivers as well. Married couples may have as many as four elderly parents living; in fact, they may have more parents or relatives in need of care than they have children living at home

or on their own. In the past, research on elder care focused on the challenges facing working adults who were caring for both children and elderly parents—the so-called *sandwich generation*—a term coined by sociologist Dorothy Miller to refer to specific generational inequalities in the exchange of resources and support.⁸ Miller's research highlighted the stress on the middle generation of employees who are caring for two groups of dependents while receiving little support. The sandwich metaphor, however, is outmoded in several respects: it does not convey that more than one generation may provide elder care or that members of any generational cohort can be both caregivers and care receivers. Nor does the image of static layers do justice to the dynamic interaction between generations, such as transfers of financial aid, sharing residential space, or exchanging personal and emotional care.

Today researchers are increasingly finding that adults may spend more years caring for their parents than caring for their children.⁹ And because families today tend to be small, middle-aged adults may have smaller sibling networks to share elder care responsibilities. In short, elder care in the United States is a demanding task, and caregivers, especially the almost 60 percent of family caregivers who are employed, are finding it harder to undertake that task alone.¹⁰

Care Work and the Dimensions of Elder Caregiving

There is an extensive body of research on family “care work” dating back to the 1960s with a study that challenged the “myth of the abandoned elderly” and showed that families were still caring for elders, but that changes in external conditions in the family, the workplace, and the community were making caregiving more challenging.¹¹

One of the contributions of recent care work research is to draw attention to the “work” aspects of caregiving. This framing contradicts personal and cultural ideas about why families care for elders and makes two related arguments: the first is that because family caregiving is largely done by women and is unpaid, it is often devalued; the second is that despite this devaluing, unpaid care work adds huge value to U.S. society in providing much needed care and “services” to the most vulnerable in the nation's population. Some scholars have tried to calculate the monetary value of unpaid care work to strengthen the argument about its value. Estimates vary from \$196 billion a year, calculated in 1997,¹² to \$257 billion a year based on a subsequent study by the United Hospital Fund in 2004.¹³ In either case, the numbers far exceed what the United States spends on home health care and nursing home care, underscoring the importance of family care.

To differentiate the work families provide from the work that professionals and paraprofessionals provide, many studies of caregiving use the terms “informal care” to refer to the care provided by families and “formal care” to refer to that provided by trained health and social service staff. The distinction creates a sharp line between the informal care that is unpaid and takes place in private homes and the formal care that is paid and takes place in institutional and community settings. The distinction, however, has been challenged by some elder care scholars who find that family caregivers of elders provide care in hospitals, rehabilitation facilities, outpatient clinics, and community agencies. Family caregivers are a “shadow workforce” in the geriatric health care system.¹⁴ Some states are piloting “cash and counseling” programs to pay families for the elder care they do, so the paid-unpaid distinction is being challenged in public policies.

Elder care entails a variety of supports and responsibilities, many of which can change in intensity and complexity over time. Cultural differences unique to elders and their families shape their views on what aging, health, and end of life mean and thus affect expectations about who provides care and what is provided.¹⁵ The variations in elder care are numerous, as the following eight dimensions illustrate.

Time Dimension

Elder care takes three forms: short-term, intermittent, and long-term. Elderly parents may, for example, have surgery that immobilizes them temporarily, but restores them to a high level of daily functioning. In such cases the care needed may be fairly intense but of short duration, and so it disrupts the caregiver's job, family, and personal life, but only temporarily. In contrast, the seven in ten care recipients who have chronic health conditions¹⁶ may require intermittent care that entails regular trips to one or more specialists, medication management, and adjustments to household and personal routines. In such cases, the caregiver is needed frequently over a longer period and may be hard pressed to integrate caregiving demands with paid work. In other cases elder care may be long-term, lasting for months or years. Such caregiving may be required on a daily basis and can seriously complicate the caregiver's ability to maintain a job, provide care for other family members, and maintain personal and community involvement.

Since 1987 the American Association of Retired Persons (now called AARP) and the National Alliance for Caregiving (NAC) have conducted several national surveys tracking the time Americans invest in elder care.¹⁷ The most recent survey, in 2009, found intermittent elder care to be the type most commonly

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provided. Caregivers surveyed in that poll report providing such care for an average of 4.6 years; 31 percent report giving such care for more than five years.¹⁸ Half of all of caregivers spend eight hours or less a week, while 12 percent spend more than forty hours. Short-term or intermittent care may evolve into long-term care as an elder's physical or mental function, or both, deteriorates.

Geographic Dimension

The distance between an elder's place of residence and that of the caregiver has a major effect on the type and frequency of care. Because some American families are mobile—about 16 percent of families move each year¹⁹—adult children sometimes live in different cities, states, or even regions from their elderly parents. According to the most recent AARP-NAC survey data, 23 percent of caregivers live with the elder for whom they are caring (co-residence is particularly common among low-income caregivers) and 51 percent live twenty minutes away.²⁰

Long-distance caregiving, however, has been on the rise over the past fifteen years.²¹ One study by MetLife finds that at least 5 million caregivers live an hour or more away from the elder for whom they care.²² Of this group, about 75 percent provide help with daily activities, such as shopping, transportation,

and managing household finances. Most long-distance caregivers share responsibilities with siblings or paid caregivers, or both. Several studies document that adult children who live near an elderly relative are most likely to provide the majority of elder care,²³ underscoring the importance of geographic location.

Residential Dimension

To move, or not to move? Many elders struggle with this question, and often turn to family caregivers for help with the answer. Most elders want to live in their own homes and neighborhoods; for some, safety and accessibility require home renovations. Family caregivers may plan, organize, and finance adaptations in an elder's living space. Not all elders and all caregivers are homeowners (some are renters), which can pose particular challenges for all parties.²⁴ When it is not feasible for elders to adapt their dwelling, moving becomes necessary. In that case, caregivers often research, plan, and organize the move. Some elders move to continuing care retirement communities that provide different types of units for residents of different abilities.²⁵ Although such communities have grown in popularity, and may relieve families of some responsibilities, the units are expensive to buy, and monthly maintenance fees are costly, thus making this option unaffordable for most elders.

A small share of elders lives in rehabilitation facilities, usually on a short-term basis. Between 5 and 6 percent of elders live in a long-term-care facility or nursing home, with caregivers making regular or intermittent trips to visit and monitor the care being provided. Most elders live in their own homes,²⁶ which must be constantly assessed for safety and the availability of community services such as transportation, social services, and recreational opportunities. Nongovernmental

organizations (NGOs) help maintain more than 10 million elders a day with long-term care supports and services so they can continue to live in their homes independently.²⁷ To help caregivers assess what is required for independent living, researchers have developed tools that can aid in choosing appropriate housing and support services.²⁸

Financial Dimension

The economic resources available to caregiving families vary widely. Upper-middle-class and affluent families usually have adequate funds to pay for elder care services, while poor families are usually eligible for a variety of subsidized services, such as home health care. The hardest-hit families are the working poor and those with moderate incomes, who are too "rich" to qualify for subsidized services but unable to pay for care themselves. Many families caring for elderly relatives encounter this type of "middle-class squeeze."

Researchers who explore the financial dimension of elder care find that cross-generational transfers are fairly common. In a 2005 study, 29 percent of baby boomers provided financial assistance to a parent in the previous year, while about a fifth received financial support from a parent.²⁹ A recent nationally representative survey of elders over sixty-five offers a slightly different picture: half of these elders say they have given money to their adult children, while about a third say they help their adult children with child care, errands, housework, and home repairs. When asked what their adult children give them, more than 40 percent report receiving help with errands and rides to appointments; about a third, help with housework and home repairs; and about a fifth, help with bill paying and direct financial support.³⁰ What is striking is that care, time, and money are

being exchanged between the generations, going both ways.

Health Dimension

Some caregivers provide help in a short-term acute health care crisis, others care for elders with one or more chronic diseases, and a third group cares for elders with long-term incurable or progressive diseases. Families are a critical resource for the nation's health care system when they care for a relative with a debilitating disease, such as dementia or Alzheimer's, for which paid care is very expensive. Giving such care, however, is a major burden on these families, who frequently find that caregiver training—both how to manage the behavior and symptoms of the elder *and* how to cope with their own feelings—is often not available.³¹

The health status of an elder determines the extent of a caregiver's involvement with personal care, often referred to as activities of daily living, such as eating, bathing, toileting, and dressing, or as instrumental activities of daily living, such as cooking, shopping, and bill paying. The health status of the elder also shapes the extent of caregivers' involvement in medical tasks such as giving medications; dressing wounds after surgery; checking weight, blood pressure, and blood sugar levels; and monitoring medical equipment. A national survey of caregivers found that more than 40 percent helped with one or more medical tasks, even though only one-third reported that they had the training to do so.³² That finding underscores the "medicalization" of the care work that families are providing for elders.

One elderly cohort that is growing is "frail elders," defined as those sixty-five and older who do not live in nursing homes, but have difficulty with at least one aspect of

independent living or are severely disabled, or both. This group numbered about 10.7 million people in 2002.³³ Analyses of a national data set showed that two-thirds of frail elders receive help—an average of 177 hours a month—with personal care from an unpaid family caregiver. More than half of that help comes from their daughters, most of whom are working.³⁴

Legal and Ethical Dimension

When significant declines in physical and mental health compromise elders' ability to manage their own affairs, it is usually the family caregiver who assumes some level of control, decision-making power, and ultimately legal authority such as power of attorney. Studies on the legal issues of elders often focus, particularly when financial resources are involved, on the caregiver as a source of interfamilial conflict and even elder abuse. A recent study of financial elder abuse, however, found that only 16.9 percent of the perpetrators were family members.³⁵

Legal issues may also require caregivers to take on complex health-related roles, such as acting as health care proxy or setting up an advance directive or DNR (do not resuscitate) order. These steps can involve complex ethical questions and decisions, such as when to discontinue life supports for a terminally ill parent. Studies on elders at the end of life show the critical role that family caregivers play once palliative care is chosen, including assisting elders with daily living, handling medications, and making medical decisions.³⁶ Using ethnographic data, a study of one elderly mother and her daughter documents how this family navigated the health care system and brought their own cultural meaning to end-of-life care.³⁷ Other studies emphasize the high degree of stress on families with terminally ill elders, showing

the unresponsiveness of some health care systems, as well as the ways in which community services can ease stress.³⁸

Emotional, Moral, and Spiritual Dimension

Much of the research on elder care explores the practical daily routines involved in personal care, health care, and housing. The emotional care that families provide, although essential to the well-being of elders, is less studied and is difficult to define. The medical anthropologist Arthur Kleinman, a caregiver for his wife with Alzheimer's, argues that the emotional part of caregiving is in essence a moral act—"an existential quality of *what it is to be a human being*."³⁹

Attending to the spiritual needs of elders for whom religious experience, practice, and faith have been important is also critical to sustaining their physical and mental health and longevity.⁴⁰ For these elders, caregivers' tasks include: spiritual and well-being assessments; using a reminiscence-and-life-review approach; identifying and facilitating contact with religious services, organizations, and clergy; and discussing end-of-life issues.⁴¹ Tailoring these tasks to an individual elder's particular faith tradition is both time-consuming and extremely meaningful.

Outsourcing Elder Care and Care Coordination

When family members cannot provide care, particularly if they are full-time workers or long-distance caregivers, or both, their job is to find an agency close to where the elder lives that will provide services for a fee. It takes time and effort to find an appropriate multiservice or aging service agency,⁴² to provide the agency with detailed personal and health information about the elder to ensure a good "client-provider fit," and to

monitor services to be sure that needs are met and the elder is comfortable with the provider. Carrying out all these tasks to find just one type of service is difficult enough; if an elder needs multiple services, the work for the family can be significant.

Many studies have documented the fragmentation in the geriatric health care and social services system, and others have called for greater care coordination to support caregivers.⁴³ The handoffs between hospitals and families, or between rehabilitation facilities and families, can often be unsafe and unsatisfying, and the need for improved communication is widely documented.⁴⁴ Given the cross-institutional complexities, some caregivers hire a geriatric care manager—often a trained social worker—to identify, monitor, and coordinate services. Hiring a care manager requires research by the family caregiver, as well as ongoing monitoring and extensive communication. The work of care coordination is a significant, often unnoticed, aspect of care many families do themselves, either because they cannot afford to hire a geriatric care manager or because they prefer to keep an eye on things themselves.⁴⁵

Elder Caregiving and Diversity

Most studies on aging and elder care treat elders and their caregivers as monolithic groups. But as the nation has become more diverse, so too has the population of elders. Elder caregiving varies by gender, race, and socioeconomic status, and families from African American, Latino, Asian, Native American, and other groups bring their own strengths and needs to the caregiving experience. Although gender, race, and socioeconomic status are treated separately below, it is important to note that these variables often intersect in powerful and important ways in the lives of caregivers. An "intersectionality"

approach shows how unequal opportunity over the life course shapes trajectories of advantage and disadvantage for elders and the families who care for them. Future research must explore multiple aspects of diversity in order to develop new policies that address the interaction between socioeconomic inequality *and* differences based on gender, race, and culture.

Gender and Elder Care

Elderly women live longer than do elderly men, and despite a lifetime of providing care to others, they are more likely than men to live alone, live in poverty, and lack care themselves when they are elderly.⁴⁶ Research on gender and caregiving has two major themes. First, the majority (67 percent) of family caregivers are women,⁴⁷ with wives providing care to spouses and adult daughters providing the majority of care to elderly parents. Second, given the persistence of gender inequality in the workforce, including the gender gap in wages, women caregivers are more likely than men to cut back on work hours or quit their jobs because of their caregiving duties and are thus left with less income, small savings, and reduced pensions.

Although women in the general population have greater elder care responsibilities than do men, recent studies reveal that employed women and employed men provide care in roughly equal numbers.⁴⁸ But gender differences persist nonetheless: employed women are more likely than employed men to provide family care on a regular basis, they spend more hours providing care, and they spend more time providing direct care such as meal preparation, household work, physical care, and transportation.⁴⁹ This finding is consistent with other evidence on gender trends in elder care showing that women tend to perform household and personal care tasks that are

physically draining and likely to interrupt daily activities, while men tend to give periodic assistance.⁵⁰ Both working and nonworking male caregivers receive more assistance with their caregiving efforts than do women; they also tend to delegate their tasks to others and to seek paid assistance to alleviate some of their caregiving responsibilities.⁵¹

Despite the growing number of men balancing work and elder care responsibilities, women are particularly vulnerable to negative work-related consequences.⁵² Women who are caring for elders generally reduce their work hours, leave the workforce, or make other adjustments that have negative financial or career implications. Some refuse overtime and pass up promotions, training, assignments that are more lucrative, jobs requiring travel, and other challenging but time-consuming job opportunities.⁵³ Many low-income women and women of color who are employed do not have sufficient flexibility or autonomy in their jobs to be able to take an elderly parent to the doctor or attend to other needs.⁵⁴

Despite feelings of satisfaction from their care, caregivers can sometimes feel burdened, socially isolated, strained, and hopeless. A recent MetLife study of working caregivers, based on a large corporate employer's health risk appraisal database of roughly 17,000 respondents, found that employed women are significantly more likely than employed men caregivers to self-report negative effects on personal well-being.⁵⁵ Caregivers in general report more physical and mental health problems than noncaregivers,⁵⁶ and more female caregivers (58 percent) report negative health effects than male caregivers (42 percent).⁵⁷ In a study assessing gender differences in caregiver health,

Martin Pinquart and Silvia Sörenson found that women had lower scores for subjective well-being and perceived physical health, as well as higher scores for burden and depression than men. The effects for women caregivers indicated a positive and statistically significant relationship.⁵⁸

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Race, Ethnicity, and Elder Care

The growing diversity of the United States makes it important for researchers to consider how race and ethnicity—both socially constructed categories—shape aging and the caregiving experience. The nation's legacy of racial oppression and structural inequality has created socioeconomic inequities in education, health, housing, income, and wealth. Many low-income men and women of color enter old age after a lifetime of cumulative disadvantage, during which limited access to economic opportunity has obstructed efforts to accumulate savings for retirement and limited access to health care has led to poorer health.

Few families from racial and ethnic minority groups use paid or outsourced care, and those who do can sometimes face structural barriers in accessing them. Although most Americans refrain from putting their elderly kin in nursing homes, Latinos, African

Americans, and Asians are least likely to do so.⁵⁹ Even elders of color with greater care needs, such as those afflicted with dementia or chronic illnesses, are more likely than whites to receive care from their children and live in the community with them.⁶⁰

Many studies show that families of color rely on extended kin networks and friends for financial assistance, material goods, domestic duties, and other supports.⁶¹ African Americans, especially, rely on networks of neighbors, friends, and fellow congregants. Language and cultural barriers often lead Chinese American and Puerto Rican caregivers to use ethnically oriented organizations in their communities for support.⁶²

Extensive social support may partially explain why racial and ethnic minority groups tend to have more favorable attitudes toward caregiving and higher caregiving satisfaction.⁶³ Studies suggest that many groups of color value mutual exchange, reciprocity, filial responsibility, and interdependence, whereas Western European and white ethnic groups value self-reliance and independence. Using well-established positive appraisal scales and coping questionnaires, several studies find a significant “race” effect, with caregivers of color such as African Americans and Latinos showing the highest appraisals of positive aspects of caregiving and higher scores on well-being measures.⁶⁴

Among some Latino groups, the extended family is expected to provide care to older relatives,⁶⁵ and Native Americans strongly value giving back to those who have provided for them, reinforcing the value of reciprocity in their culture.⁶⁶ White caregivers report greater depression and view caregiving as more stressful than do caregivers of color.⁶⁷ Studies that have addressed racial and ethnic

differences among caregivers generally have not focused on working caregivers. One that does finds that employed white caregivers report significantly higher work demand and strain than Latino and black working caregivers.⁶⁸

Although research consistently reveals significant differences in caregiver outcomes by race, findings may vary because of differences in recruitment strategies, in criteria for inclusion and exclusion, in construct measurement, in research instruments, and in statistical techniques. The studies also vary in sample size and sampling strategy and rarely use random assignment or national probability sampling to posit any causal relationships between variables. To strengthen generalizability, accuracy of statistical findings, and comparability across studies, researchers will have to use more diverse and random sampling strategies as well as experimental and mixed qualitative and quantitative methodologies.⁶⁹

Socioeconomic Status and Elder Care

Although researchers do not often explore the implications of socioeconomic status—defined by education, occupational status, family income, net worth, and financial assets—for elder care, it can nevertheless have important effects on elders' quality of life and the kind of care their families can provide.

In the first place, many low-income elders have insufficient resources. More than half of all senior households (54 percent) cannot meet their expenses even using their combined financial net worth, Social Security benefits, and pension incomes.⁷⁰ Among older persons reporting income in 2008, 20.3 percent had less than \$10,000.⁷¹ Such economic challenges often increase the financial

burden, hardship, and strain on their families. Many studies do show that families with higher socioeconomic status tend not to provide physical care themselves, and instead tend to purchase elder care services, provide financial gifts, buy alternative lodging, and remodel homes to accommodate an elder.⁷²

A scarcity of resources makes working poor and working-class caregivers more likely to provide direct care themselves rather than to hire professional care managers. When low-income families do purchase formal services, they use them only for short periods. Middle-class and higher-income caregivers hire elder care assistance for longer periods or until their resources run out.⁷³

Responses from Employers and Government

Researchers have also investigated how employers and government are responding to the challenges families face in providing elder care. Are employers, for example, providing working caregivers of elders with “family-friendly” benefits and policies? Are federal, state, and local governments meeting the needs of elders and caregivers with public policies? We explore the adequacy of their responses to the needs of both elders and family caregivers to gain insight into what policy changes may be needed in the future.

Responses from Employers

Given the aging of the population and the high rate of female labor force participation, the share of elder caregivers who are employed has been growing over the past thirty years and is expected to continue, nearing the percentage of employees with child care responsibilities. One of the earliest national estimates, based on data from the 1982 National Long-Term Care Survey and its companion National Informal Caregivers

Survey, was that 15.8 percent of elder caregivers were employed,⁷⁴ 9 percent had quit their jobs because of elder care responsibilities, and 20 percent were experiencing conflict between work and elder care.⁷⁵ Surveys conducted in the late 1980s and 1990s found the share of employed caregivers rising significantly, up to 64 percent in 1997.⁷⁶ One 2010 study found that six in ten family caregivers are employed;⁷⁷ another found that considered as a group, 50 percent of employed caregivers of elders work full time, and 11 percent work part time. In the coming years, employers will need to respond to the elder care needs of their workforce lest they compromise the performance of their firms and the retention of some of their most valued employees.

Research on work and family conflict is extensive, and many studies focus on work and elder care for employees.⁷⁸ Beyond general feelings of role conflict, working caregivers in one study report using their own sick leave or vacation hours to accommodate elder care needs (48 percent), cutting back on hours or quitting their job (37 percent), taking an additional job or increasing their hours to get funds for elder care expenses (17 percent), taking unpaid leave (15 percent), and leaving their job for a different one (14 percent).⁷⁹ Many studies report negative health consequences for employed caregivers, including increased risk of stress and depression, diabetes, hypertension, and even premature death.⁸⁰ If caregivers cut back work hours, take unpaid leaves, or leave their jobs, the negative effects can go beyond the individual caregivers themselves to include whole families. For example, a MetLife study documented negative financial repercussions for families from short-term income losses, long-term losses of retirement savings, and lost opportunities for career advancement.⁸¹

Researchers are also examining the policies and programs of employers to address their employees' elder care needs; rough estimates are that from 25 to 50 percent of employers offer these programs.⁸² Large firms are more likely than small companies to have elder care programs, and a 2003 study estimates that 50 percent of large corporations offer such programs.⁸³ For small and mid-sized firms, the estimate was 26 percent in 2006 and 22 percent in 2007.⁸⁴ Studies on how the recent recession affected elder care programs are just now becoming available; one, for example, shows that most employers are maintaining workplace flexibility, although reduction of hours may translate into reduction in pay, so increased flexibility entails both costs and benefits.⁸⁵

Elder Care Assistance Programs, introduced by companies during the late 1980s, have grown in scope. The early programs—paralleling those developed to support workers with young children—included resource and referral services to locate elder care services in the elder's community, and flexible spending accounts for putting aside funds on a pre-tax basis to cover elder care expenses.⁸⁶ During the 1990s, some companies expanded elder care benefits through Employee Assistance Programs or new "work-life programs" to include flexible work arrangements (58 percent), personal or sick leaves (16 percent), and access to short-term emergency backup care when a paid caregiver was unexpectedly absent (4 percent).⁸⁷

During the mid-1990s, some researchers began exploring the question of whether employees made use of elder care benefits. Early studies found that use rates were low, although the range was fairly wide—from 2 to 34 percent—with use by employees in private-sector firms lower than use by

public-sector employees.⁸⁸ Most scholars and human resource managers hypothesize that rates were low because employers had not publicized the programs that were available. A 2007 survey of human resource managers at Fortune 500 companies found that flexible work arrangements and leave programs were the most highly utilized and had the best use-to-cost ratio.⁸⁹ Emergency short-term home care had the lowest use rates and highest cost, and thus the worst use-to-cost ratio. In open-ended questions, respondents focused on the need for better communication about elder care programs; the importance of supervisors actively encouraging the use of these programs; and the difficulty of countering negative perceptions about these programs.⁹⁰ Although elder care benefits appear to boost employee recruitment and retention, that link has not been conclusively demonstrated.⁹¹

To date, the needs of employed elder caregivers far exceed the employer response, and elder care assistance tends to be offered only by the largest employers. Some studies about “family-responsive” workplaces do not even mention elder care as a benefit needed by families,⁹² and the findings of studies that do focus on elder care have less than encouraging findings. The 2009 Age and Generations study found that employees who are caring for elders had less access to flexible work arrangements than did employees who were caring for their children or who had no dependent care responsibilities, that employees in the sandwich generation were less likely to be included in new projects based on teamwork than workers with no elder care demands,⁹³ and that employees who provide elder care had lower job security than other groups.⁹⁴ Elder care programs are still less frequently offered than child care programs, and a 2006 study found that although almost

three-quarters of employers offered some child care assistance, only one-third offered elder care assistance.⁹⁵

What accounts for employers’ lag in offering elder care assistance? And how can workplaces make elder care a key component of the work-family or work-life agenda? Elder care may have received less attention than child care because ageism and denial about aging is deeply entrenched in U.S. culture. As Muriel Gillick, a palliative care physician, argues, “Contemporary Americans are eager to prevent, obliterate, or at least conceal old age . . . in keeping with the belief that we can control our destiny.”⁹⁶ This denial can lead employers to ignore or minimize the elder care needs of their workforce, using arguments about high costs and low utilization to justify having few elder care programs.

Some work-family scholars argue that developing a family-friendly workplace is a long-term process with three distinct stages. In the first stage the goal is to promote the recognition of a particular work-family issue as a visible, legitimate need. In the second stage the goal is to implement and then refine specific programs, including effective communication and supervisor training. The third stage involves institutionalizing the new work-family programs into the culture of the workplace to heighten program reach and effectiveness.⁹⁷ In this evolutionary paradigm, different percentages of companies are at different stages in responding to elder care. Many private-sector firms and the majority of small and mid-sized firms are still in the first stage, struggling to recognize elder care programs as a legitimate need of the workforce. Roughly a third of firms are in the second stage, starting, developing, and retaining elder care programs. Only a minority of firms—mainly large companies—are in

Table 1. Institutional Responses to Aging and Elder Care from Government

Name of policy	Year started	Basic goal	Eligibility	Source of funds
Social Security Act	1935	Provide income for people who have retired from paid employment	Work in a Social Security-covered job for 10 years or more, can start collecting at age 62 up to age 70, widow(er)s at 60, disabled at 50	Payroll taxes and self-employment contributions, paid into Social Security Trust Fund by employees and employers
Medicare	1965	Coverage of health care costs, including Part A: hospital care, Part B: outpatient care, and Part D: prescription drugs	People 65 and older, who had Medicare-covered employment, not linked to income earned	Employers and employees pay taxes for Part A, funds from SSI checks cover Part B, and Part D paid for by Medicare plus private insurance
Medicaid	1965	Cover health care costs for low-income children and families, long-term care for elderly and/or disabled	Pregnant women, children, teens, elders, blind, and disabled with low incomes	Means-tested, funded by state and federal funds, managed by states
Older Americans Act (OAA)	1965	Promote the delivery of social services to aging population via Administration on Aging (AoA) and state agencies	National Elder Locator for all families, some meal programs, housing, and services for low-income elders	Taxes and other government funds, most funding for social service programs, rest goes to jobs program, research, and training
Family and Medical Leave Act	1993	Twelve weeks of job-protected unpaid leave with continuation of health benefits for own serious health condition, and/or care of seriously ill parent, child or spouse, and child rearing	Workers at firms with 50 or more employees within 75-mile radius, who worked 1,250 hours and 12 consecutive months	Payroll tax in California and New Jersey, otherwise unpaid Administrative costs funded by states and U.S. Department of Labor
National Family Caregiver Support Program	2000, under OAA reauthorization	Referrals for services/ respite care, information, counseling, training, and support groups for family caregivers	Persons of any age who serve as unpaid caregivers for persons 60 years or older	Funds from Older Americans Act, Title III E

the third stage. Making the “family-friendly workplace” an “elder-care-friendly workplace” remains an unrealized project for many employers.

Responses from Government

During the nineteenth and twentieth centuries the United States gradually transferred responsibility for elder care from the family to the government, from the private sphere to the public sphere.⁹⁸ But despite landmark twentieth-century legislation, it can be argued that the United States lacks the full range of public policies needed to address the aging of the population, and that families still bear the primary responsibility.

Table 1 briefly summarizes six public policies that are key to the well-being of elders and their family caregivers. Some have enhanced health and income security for elders; others have enhanced the supports available to both employed and nonemployed family caregivers. We briefly address the strengths and weaknesses of some of these policies to suggest possible areas for policy expansion.

Social Security is critical to providing a basic level of financial support and security to elders. Several issues, however, weaken its effectiveness. Initially the system strengthened intergenerational ties because those who retired—only 5.2 percent of the population

was sixty-five or older in 1930—were reaping benefits based on the productivity of younger workers. But in the decades ahead, more people will be needing retirement income, and fewer young workers will be available to replenish Social Security funds, thus putting pressure on the younger generation and creating tension between generations.⁹⁹ In addition, because Social Security is based on wages in the paid labor force, women who delayed work, interrupted work, or never entered the workforce because of family caregiving responsibilities have smaller benefits in old age than men (though at the death of her spouse, a woman is eligible to collect a “survivor” Social Security benefit).

Medicare, a second foundational piece of economic security for elders, ensures coverage of many health care costs. It, too, however, is problematic. Originally enacted to cover the costs of acute care and hospitalization, Medicare does not provide adequate insurance for chronic illnesses, those common to most elders. Medicare does not reimburse hospitals fully for the care they provide, so many hospitals have shortened patient stays, creating difficulties for caregivers when an elder is prematurely discharged to rehab or to home. Medicare will cover a stay in a skilled nursing facility only if daily nursing or rehab services are needed, and will cover ten hours a week of home care only if skilled nursing care is required. Finally, Medicare does not cover the cost of long-term care.

Medicaid, the third key government policy, is the largest source of payment for nursing home care, and it will become increasingly important as the nation’s population ages. In 2008, nearly 41 percent of the nation’s nursing facility care was paid by Medicaid, averaging nearly \$30,000 for each beneficiary.¹⁰⁰ In most states, Medicaid also pays for some long-term

care services at home and in the community. Although eligibility varies from state to state, those elders who are eligible for Medicaid assistance must have limited assets and incomes below the poverty line. They also must contribute all or most of their available income toward the cost of their care. Many elderly who enter nursing homes pay for their own care initially. Once their resources have been depleted, however, they are covered by Medicaid. According to a study by Brenda Spillman and Peter Kemper, 16 percent of Medicaid users began by paying their own way in long-term nursing facilities, exhausted their resources, and converted to Medicaid; 27 percent were covered by Medicaid when they were admitted to the nursing home.¹⁰¹

Despite their many provisions for elder support, Medicaid and Medicare leave significant gaps in coverage.

Medicaid often provides supplemental services to fill gaps left by Medicare. The Centers for Medicare and Medicaid Services estimated that Medicaid provided some additional health coverage for 8.5 million Medicare beneficiaries in 2009.¹⁰² In addition, Medicare and Medicaid jointly fund a model program called PACE (Program of All-Inclusive Care for the Elderly), in which an interdisciplinary team, consisting of professional and paraprofessional staff, assesses participants’ needs, develops care plans, and delivers all services (including acute care services and nursing facility services when necessary), which are

integrated for a seamless provision of total care. The program is available to individuals fifty-five and older who are certified by the state as nursing home eligible and meet the income and assets requirements to qualify for Medicaid.¹⁰³

Despite their many provisions for elder support, Medicaid and Medicare leave significant gaps in coverage. The new Patient Protection and Affordable Care Act of 2010 should ease some of the burdens by expanding drugs covered by Medicare Part D, the prescription drug program, improving prevention benefits such as free annual wellness visits, and changing the cost of Medicare Advantage plans. Mechanisms to control or reduce Medicare spending may or may not benefit elders, and a new Medicare and Medicaid Innovations Center holds promise of testing new payment and service delivery models that could benefit elders and their families.

A fourth important policy with implications for elder care is the Older Americans Act (OAA), passed as part of Lyndon Johnson's "Great Society" reforms and the first public policy to recognize the importance of community-based NGOs in the elder care system. Although the OAA signaled a significant effort to systematize and broaden access to elder services, studies evaluating its effectiveness have had mixed findings. For example, studies of home care programs have found that although providers have had some success in managing the daily practical needs of elders, they have been less successful in dealing with emergencies or significant health issues or levels of impairment.¹⁰⁴ Studies have shown that home care is more effective than inpatient care and reduces the length of hospital stays, but little data are available on how OAA programs affect measures of quality of life for elders or caregivers.¹⁰⁵ A book on

OAA's Long-Term Care Ombudsman Program summarizes a number of issues cited in studies of other OAA programs. These include: a misalignment of resources and goals, which compromises program effectiveness; a lack of coordination between OAA programs and resources, which diminishes program effectiveness; and a lack of elder or caregiver empowerment to take control of elders' health care or make positive programs more sustainable and cost-effective.¹⁰⁶

The Family and Medical Leave Act (FMLA) is the only law that deals specifically with the challenges of working and providing elder care. A bipartisan commission that conducted two nationally representative random-sample surveys to study the impact of the FMLA on employers and employees reported to Congress in 1996 that the law was not the burden to business that some had anticipated.¹⁰⁷ In terms of ease of administration and impact on productivity, profitability, and performance, the law was found either to have "no noticeable effect" or, in some cases, to produce cost savings. On the employee side, the FMLA was found to be a boon to families in their caregiving roles. Most leaves were short, and concerns that employees would abuse the law and use it for recreational time off proved unwarranted. In fact, some "leave-needer" did not take advantage of the law because they could not afford an unpaid leave. The surveys were repeated in 2000 with largely comparable results for employers and employees.¹⁰⁸ The major complaint from the employer community was the difficulty of administering "intermittent leaves," although employees find that type of leave useful for chronic health problems. Between the 1995 and 2000 surveys there was a statistically significant increase in the use of FMLA for elder care.¹⁰⁹

From a policy perspective, the FMLA is like a minimum labor standard. It provides valuable protections to workers, but has limitations that hamper its effectiveness. Access to FMLA, for example, is restricted to about 55 percent of the workforce because of eligibility requirements for firms and employees. The definition of “family” is limited to parent, child, and spouse, depriving many elderly relatives such as grandparents or aunts and uncles, as well as those who are members of the lesbian, gay, bisexual, and transgendered (LGBT) community or who are not legally married, of coverage. And because the leave provided is unpaid, it is difficult for low-income workers to use. Recently two states, California and New Jersey, passed laws to establish paid leave programs, and a new study of the California law yields useful information about the applicability of these models for other states.¹¹⁰ These new state policies are contemporary examples of the historical research of sociologist Theda Skocpol, who showed that federal policy is often driven by demands from local citizen associations and the actions of state legislatures.¹¹¹

Finally, the National Family Caregiver Support Program (NFCSP) is the first federal law to acknowledge fully the needs of caregivers regardless of their employment status. Preliminary studies have shown that the program is expanding caregivers’ access to elder care information and providing needs assessments, support groups, and stress reduction programs.¹¹² Although NFCSP offers many excellent services, such as respite care, counseling, and training for family caregivers, the funds available to deliver them are limited, particularly in the area of respite care.¹¹³ As with many OAA programs, the goals of the statute are not matched by the resources needed for nongovernmental agencies to carry them out. Although the

NFCSP has brought greater attention and supports to families caring for elders, particularly resources to promote caregiver health and prevent caregiver burnout, inadequate resources impair its effectiveness. Proposals for tax-based supports for caregivers or programs to pay family caregivers are appearing in state legislatures, but have yet to gain traction in Congress.

When government and employers cannot provide adequate support for elder care, family caregivers often rely on nongovernmental organizations, such as health care providers and community-based aging service agencies. Although NGOs are often created and funded by government, they are not direct policy-making organizations, and their role is beyond the scope of this article. Caregivers do, however, receive significant support, information, and services from these groups, including faith-based organizations, neighborhood centers in communities of color, LGBT advocacy organizations, and educational organizations. Because so many elder caregivers are employed, NGOs that provide services for elders and their caregivers must take the needs of employees into account.

Creating an Aging-Friendly Society

The challenges faced today by elders and their family caregivers are enormous and will continue to increase during the twenty-first century as the population ages. Families alone cannot provide elder care, employers alone cannot provide all the supports employed caregivers need, and the government alone cannot provide or fund all the elder policies required. A large-scale, cross-sector initiative is needed to coordinate efforts at the national, state, and local level and to support all citizens from diverse cultures and income levels as they age.

Public policies must move in a universal direction, like Social Security and Medicare, to help transform U.S. communities and make housing, transportation, and open space accessible to all elders. There is a pressing need to better integrate nongovernmental organizations in the health care and social service sectors and to ensure they are culturally responsive. Employers must be encouraged to give employees in both professional and hourly jobs access to flexible work arrangements including part-time work, paid leave policies, paid sick days, and other “elder-friendly” workplace benefits. Overall, these groups must work together to create

a culture in which aging is seen as a natural part of the life course and caregiving is seen as a multigenerational enterprise of great value to children, adults, elders, and society.

Elders themselves and their family caregivers, as well as the public and private sectors, must build support for social investment in the next generation. Today’s children will be the workers, citizens, and family caregivers who will care for the growing U.S. elderly population tomorrow. Focusing on children’s healthy development and education will build their capacity to provide supportive care for the elders of future generations.

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