Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving

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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, up from an estimated \$375 billion in 2007.

Introduction

Family support is a key driver in remaining in one's home and in the community, but it comes at substantial costs to the caregivers themselves, to their families, and to society. If family caregivers were no longer available, the economic cost to the U.S. health care and long-term services and supports (LTSS) systems would increase astronomically.

This report, part of the Valuing the Invaluable series on the economic value of family caregiving, updates national and individual state estimates of the economic value of family care using the most current available data.

It finds that 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, up from an estimated \$375 billion in 2007.

This report also explains the contributions of caregivers, details the costs and consequences of providing family care, and provides policy recommendations to better support caregiving families.

Karen's story (see page 2) is all too familiar to the approximately one in four U.S. adults who experience the everyday realities of caring for an adult family member, partner, or friend with chronic conditions or disabilities.

Family members often undertake caregiving willingly, and many find it a source of deep satisfaction and meaning. That said, caregiving in today's economic climate and fragmented systems of health care and LTSS can have a significant impact on the family¹ members who provide care.

The "average" 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.²



One Caregiver's Story

Over the last three months, Karen has become increasingly anxious and depressed. She never imagined that the events of the past four years would lead to this amount of stress. Her 83-year-old mother, with hypertension, Alzheimer's disease, and rheumatoid arthritis, moved in, after a hospital stay related to complications from an enlarged bladder.

As a single mom with one son in college, Karen's life is now consumed with the role of care coordinator and service provider. In addition to working a demanding full-time job as a legal secretary, her days are filled with coordinating multiple health care providers, arranging transportation and home-delivered meals, managing multiple, complex medications and other health-related tasks, handling challenging behavior issues, and much more.

Although her mother attends adult day services three times a week, her cousin comes in during the other weekdays, and a home health aide or her son helps on weekends, she is finding it difficult to balance everything and is exhausted at night. She can't even remember the last time she visited with her friends or spent time gardening. Karen's job has some flexibility, but she has used up her vacation leave and now finds herself having to take time off without pay. That leads to even more stress because it is her salary that helps pay for her son's college tuition and keeps things afloat.

Through all of the visits with her mother to multiple health care providers, the arranging and patching together of services and supports while she is at work, and during and after several of her mother's hospital stays, there was always an expectation, from others as well as herself, that she would be able to handle the situation, whatever it was, just fine.

Although she had been experiencing a bad cough for the past few weeks, she did not feel she had the time to have it checked. She was just too busy. Several days later she became extremely ill and collapsed at work. Her initial thought was, "I am just tired." She was hospitalized for pneumonia. It was not until her own health scare that anyone asked her what she, Karen, needed—not just to help care for her mother or her son, but also to care for herself.

This report underscores the magnitude of these unpaid contributions to society. It highlights why family care matters to older people and adults with disabilities and to the nation's health care and LTSS systems. In addition, it describes what caregivers do, summarizes research about the impact of family care on caregivers themselves, and illustrates how family caregiving helps to improve quality of care and reduce the use of nursing home and inpatient hospital care. Finally, it shines a light on the increasing importance of family caregiving on the public policy agenda and recommends

ways to better support caregiving families through public policies and private sector initiatives.

Updating the National Estimated Economic Value of Caregiving

This report estimates the economic value of family caregiving at \$450 billion in 2009 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.

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).

The estimate of 42.1 million represents the number of caregivers providing care at *any given point* in time. Since some episodes of caregiving begin or end during the year, the total number of individuals providing care *during the year* is significantly higher, estimated at 61.6 million.

For a detailed discussion of data sources, methodology, and estimates, see appendix A, page 23. For information on the number of caregivers and economic value at the state level, and the ratio of the economic value of caregiving to Medicaid spending by state, see appendix B, page 26.

How Much Is \$450 billion?

Some benchmarks can help to put this figure in more meaningful context. The estimated \$450 billion is—

- More than total Medicaid spending in 2009, including both federal and state contributions for both health care and LTSS (\$361 billion)³
- Nearly four times Medicaid LTSS spending in 2009 (\$119 billion)⁴
- More than twice total paid LTSS, regardless of payer source (\$203 billion in 2009)⁵
- As much as the total sales of the world's largest companies, including Wal-Mart (\$408 billion in 2009, the most of any company) and the three largest publicly held auto companies

- combined (Toyota, Ford, Daimler: total \$439 billion)⁶
- Approaching total expenditures for the Medicare program (\$509 billion in 2009)⁷
- Almost \$1,500 for every person in the United States (307 million people as of July 1, 2009)⁸
- About 3.2 percent of the U.S. gross domestic product (\$14.1 trillion in 2009)⁹
- Almost as much as the gross domestic product of Belgium, the 20th largest economy in the world (\$471 billion in 2009)¹⁰

Previous Estimates of the Economic Value of Family Caregiving

The estimate of \$450 billion in economic value is consistent with prior studies, spanning more than a decade, all of which have found that the value of unpaid family care vastly exceeds the value of paid home care. Previous reports in the Valuing the Invaluable series have estimated the value at \$350 billion in 2006 and \$375 billion in 2007. Earlier estimates have shown steady growth in the economic value of family care from about \$200 billion in 1996.

Of the \$75 billion increase in estimated economic value between 2007 and 2009, 57 percent or about \$43 billion was due to an increase in the number of family caregivers and hours of care (a 23 percent increase in the number of caregivers, and a 9 percent increase in the number of bours of care), and 43 percent or about \$33 billion was due to an increase in the estimated economic value per hour from \$10.10 in 2007 to \$11.16 in 2009.

Recently, the Deloitte Center for Health Solutions and the Deloitte Center for Financial Services estimated the value of unpaid "supervisory care" at \$199 billion in 2009.¹³ This construct is a narrower definition of family caregiving, and is not necessarily inconsistent with our broader estimate of \$450 billion for the same year.¹⁴

Why Family Care Matters

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. 15 Such family care was typically short term, because most people did not survive to old age: They died from acute, rather than the chronic conditions of today, until the advent of antibiotics in the twentieth century.¹⁶ The average lifespan in 1900 was just 47 years. Today, average U.S. life expectancy is 78 years, and by 2020 will be nearly 80 years.¹⁷

Today, families remain the most important source of support to older adults. Many individuals who provide assistance and support to a loved one with chronic illness or disability do not identify themselves as "caregivers" but rather describe what they do in terms of their relationship with the other person: as a husband, wife, partner, daughter, daughter-in-law, son, grandson, niece, or close friend, for example. An estimated 83 percent of Americans say they would feel very obligated to provide assistance to their parent in a time of need. ¹⁸

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.¹⁹

Individuals with complex chronic health conditions and functional limitations rely on their families for personal assistance and for coordination of care over extended periods of time. They are more likely to see multiple health professionals, receive services in multiple settings, and experience numerous transitions between care settings, as well as to need supportive services to help with ADLs, transportation needs, and other social supports.²⁰ In 2006, health care costs for people with both chronic conditions and functional limitations were at least three times higher than for people with only chronic conditions (\$11,284 versus \$3,641).²¹

Individuals and their families generally view chronic illness and disability from the perspective of the "whole person," not as separate, discrete services or treatments. Consequently, family caregivers frequently experience the enormous fragmentation of both health care and LTSS systems that are not set up to meet their needs or those of the people for whom they care.²² However, shortages of direct care workers, such as home health aides, or inability to pay for adequate services can leave many family caregivers with no alternative but to provide care themselves.

What Caregivers Do: The New Normal

Family caregivers serve numerous roles:

- Providing companionship and emotional support
- Helping with household tasks, such as preparing meals
- Handling bills and dealing with insurance claims
- Carrying out personal care, such as bathing and dressing
- Being responsible for nursing procedures in the home

Today's family caregivers monitor chronic and sometimes acute medical conditions as well as provide LTSS at home.

- Administering and managing multiple medications, including injections
- Identifying, arranging, and coordinating services and supports
- Hiring and supervising direct care workers
- Arranging for or providing transportation to medical appointments and community services
- Communicating with health professionals
- Serving as "advocate" for their loved one during medical appointments or hospitalizations
- Implementing care plans
- Playing a key role of "care coordinator" during transitions, especially from hospital to home²³

Assisting with transportation needs is a major part of family caregiving. Nearly four in ten (39 percent) Medicare beneficiaries report being accompanied to routine medical visits, typically by spouses or adult children.²⁴ A recent analysis found that family and friends provide 1.4 billion trips per year for older relatives (age 70+) who do not drive. Adult children provide 33 percent of these trips.²⁵

The impact of shorter hospital stays, limited hospital discharge planning, and the spread of home-based medical technologies is reflected in the complex and physically demanding nursing tasks that family caregivers

are increasingly carrying out in the home. They often have little training or preparation for performing these tasks, which include bandaging and wound care, tube feedings, managing catheters, giving injections, or operating medical equipment.²⁶ Estimates of the proportion of family caregivers handling these health-related tasks in the home range from 23 percent to more than 53 percent.²⁷

The Costs of Family Caregiving

From the earliest research, family caregivers were portrayed as the "hidden patients" who needed support and care themselves to address the negative impact their relative's illness or disability was having on them.²⁸

A key theme to emerge from systematic reviews of family caregiving studies over the past 30 years is that family care can have negative effects on the caregivers' own financial situation, retirement security, physical and emotional health, social networks, careers, and ability to keep their loved one at home. The impact is particularly severe for caregivers of individuals who have complex chronic health conditions and both functional and cognitive impairments.

Financial Toll and Direct Out-of-Pocket Costs

The economic downturn has affected most American families, including those who are caregiving. In 2009, more than one in four (27 percent) caregivers of adults reported a moderate to high degree of financial hardship as a result of caregiving. ²⁹ Another study found that one in four (24 percent) caregivers said they had cut back on care-related spending because of the economic downturn. ³⁰ One recent online survey found that six out of ten (60 percent) caregivers surveyed were concerned

about the impact of providing care on their personal savings, and more than half (51 percent) said that the economic downturn had increased their stress about being able to care for their relative or close friend.³¹

Many family caregivers make direct out-of-pocket expenditures to help support a family member or friend with a disability or chronic care needs. In one national survey of women, about one in five (21 percent) report that caregiving strains their household finances.³² A recent online survey found that more than four in ten (42 percent) caregivers spend more than \$5,000 a year on caregiving expenses.³³

Another survey taken before the economic downturn also found that out-of pocket spending was high for family caregivers, especially those with low incomes and those providing care at a distance. 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 in 2007. Longdistance caregivers had the highest average annual expenses (\$8,728). Those with the lowest incomes (less than \$25,000 a year) reported spending more than 20 percent of their annual income on caregiving expenses. To pay for caregiving expenses, one in three (34 percent) caregivers surveyed said they used their savings, and nearly one in four (23 percent) cut back on spending for their own preventative health or dental care. To manage the out-of-pocket caregiving expenses, nearly four in ten (38 percent) said they reduced or stopped saving for their own future, potentially putting their own financial security at risk. 34

Impact of Caregiving on Work

The great majority (74 percent) of family caregivers have worked at a paying job at some point during their caregiving experience, and more than

half (58 percent) are currently employed either full-time or part-time, balancing work with their caregiving role.³⁵ When it becomes stressful to juggle caregiving activities with work and other family responsibilities, or if work requirements come into conflict with caregiving tasks, some employed caregivers make changes in their work life.

Nearly seven in ten (69 percent) caregivers report making work accommodations because of caregiving. These adjustments include 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 a high burden of care, or those who live with their care recipient are especially likely to report having to make workplace accommodations.³⁶

Lost Wages and Retirement

Family caregivers can face financial hardships if they must leave the labor force owing to caregiving demands. Not only may they lose foregone earnings and Social Security benefits, but they also can lose job security and career mobility, and employment benefits such as health insurance and retirement savings. There is evidence that midlife working women who begin caring for aging parents reduce paid work hours³⁷ or leave the workplace entirely.³⁸

A recent analysis estimates that the lifetime income-related losses sustained by family caregivers age 50 and over who leave the workforce to care for a parent are about \$115,900 in wages, \$137,980 in Social Security benefits, and conservatively \$50,000 in pension benefits. These estimates range from a total of \$283,716 for men to \$324,044 for women, or \$303,880 on average, in lost income and benefits over a caregiver's lifetime.³⁹ Evidence suggests

that assuming the role of caregiver for aging parents in midlife not only has a greater economic impact on female caregivers' retirement years⁴⁰ but also may substantially increase women's risks of living in poverty and receiving public assistance in old age.⁴¹

During the recent economic downturn, caregivers faced conflicting pressures and economic consequences. One study found that employed caregivers were either less willing to take time off from work to provide care (50 percent) or were faced with having to work more hours or get an additional job (33 percent) to cover caregiving costs. More than four in ten (43 percent) employed caregivers have had their work hours or pay cut since the economic downturn.⁴² 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.⁴³

Lost Productivity and Higher Health Care Costs

Caregiving has economic consequences not only for the caregiver but also for employers, especially in lost productivity and higher health care costs. About 42 percent of U.S. workers have provided elder care in the past five years, and nearly one in five (17 percent) is estimated to currently be providing care and assistance for older relatives or friends. Just under half (49 percent) of the workforce expects to be providing elder care for a family member or friend in the coming five years.⁴⁴

It has been estimated that U.S. businesses lose up to \$33.6 billion per year in lost productivity from full-time caregiving employees. These costs include those associated with replacing employees, absenteeism, workday distractions, supervisory time, and reductions in hours from full-time to part-time. The average annual cost

to employers per full-time employed caregiver is \$2,110.45

Recent research shows a link between employed family caregivers of older relatives and their health care costs. In this study, employers were found to be paying about 8 percent more for the health care of employees with eldercare responsibilities compared to noncaregiving employees, potentially costing U.S. businesses an additional estimated \$13.4 billion per year. Both younger employees (age 18 to 39) and older employees (age 50+) providing care for an older relative were more likely to report fair or poor health in general, and they were significantly more likely to report depression, diabetes, hypertension, or pulmonary disease than noncaregivers of the same age. This finding suggests that the challenge of eldercare responsibilities in the workplace is an important factor in the health care costs of businesses. 46

Impact on Physical and Emotional Health

The work of caregiving has a substantial impact on health and well-being. An extensive body of research finds that providing care to a chronically ill family member or close friend can have profound negative effects on the caregiver's own physical and psychological health, increase social isolation, and adversely impact quality of life and well-being.⁴⁷ More than two out of three (69 percent) family caregivers responding to an online survey said that caring for a loved one was their number one source of stress, ahead of the economic downturn and other family health problems.48

Caregivers commonly experience emotional strain and mental health problems, especially depression. A review of studies suggests that between 40 and 70 percent of family caregivers of older adults have clinically significant symptoms of depression, with about one-fourth to one-half of these caregivers meeting the diagnostic criteria for major depression.⁴⁹

Research has shown that caregivers have poorer physical health than noncaregivers, with an estimated 17 to 35 percent of family caregivers perceiving their health as fair to poor. Family caregivers face chronic health problems of their own and health risks, such as heart disease, hypertension, such as heart disease, hypertension, stroke, so poorer immune function, hypertension, slower wound healing, hypertension, highly stressed use of psychotropic drugs, and even death among highly stressed spouse caregivers.

Caring for a spouse with a dementing illness like Alzheimer's disease is particularly stressful and is associated with depression, physical health problems, sleep problems, social isolation, mortality, and a greater risk of the caregiver's developing dementia. Caregivers of people with dementia were 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.

Because family caregivers often do not have free time for themselves or to be with others, they frequently experience social isolation from a loss of social contacts⁶² or from the difficulties in trying to identify and navigate practical community services to help them in their caregiving.⁶³ More than half (52 percent) of family caregivers say that their caregiving responsibilities take them away from friends or family members. Caregivers who experience social isolation also experience high levels of caregiver stress.⁶⁴

Importance of Caregiving to the Health Care and Long-Term Services and Supports Systems

Family caregivers are an essential part of the workforce to maintain the health care and LTSS systems for the growing numbers of people with complex chronic care needs. Family caregiving has been shown to help delay or prevent the use of nursing home care.⁶⁵ There is also growing recognition of the value of family members to the delivery of health care, and the ways families influence health care decisions, treatment, and outcomes.⁶⁶

The vast majority of older adults with disabilities living in the community receive family care.

Two out of three (66 percent) older people with disabilities who receive LTSS at home get *all* their care exclusively from their family caregivers, mostly wives and adult daughters. Another quarter (26 percent) receives some combination of family care and paid help; only 9 percent receive paid help alone.⁶⁷

A recent analysis of 20-year trends in family caregiving and LTSS found that until the mid-1990s, family care was being augmented by some paid help, but that trend has reversed, and "more family caregivers today are left to carry the load alone." Most recently, the increasing reliance on families to provide care may be exacerbated by the economic downturn, as some older adults may no longer afford paid help in the home.

Evidence suggests that more family caregivers are assisting older family members or friends with higher rates of disability than in the past, and are more likely to be providing hands-on and often physically demanding and intimate personal help with activities such as bathing or using the toilet.⁶⁹ Because high levels of caregiver stress are a strong predictor of nursing home entry, reducing major stresses on family caregivers, such as physical strain, frequent sleep disturbances, and financial hardship, would reduce the rate of nursing home admission.⁷⁰

Families are the main pipeline for managing continuity of care for their loved ones, and they are viewed as the "continuity connectors" in their role as the "eyes and ears" for communication and coordination with a range of health professionals and community service providers.⁷¹

One study found that 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 (40 percent) older adults received care from any physician they had seen at least once in a doctor's office in the prior year. The presence of family members during physician visits has been shown to facilitate communication and increase patient satisfaction.

Health care trends—including medical advances, shorter hospital stays, limited discharge planning and transitional care, fewer Medicare home health visits, and expansion of home care technology—are placing increasingly complex and costly responsibilities for the care of frail older people and persons with disabilities on family caregivers.

Studies have shown that caregiver burden or depression is associated with problematic discharges, ⁷⁴ while the absence of a family caregiver has been linked to hospital readmissions. ⁷⁵ Problematic discharges and the risk of rehospitalizations can occur when the

The unpaid contributions of family caregivers fill big gaps in health care and LTSS.

family caregiver feels unprepared to bring a loved one home after discharge from a hospital. Often, this is due to an absence of care coordination, poor communication from health care providers, and a lack of follow-up care and supportive services. Family members are now asked to assume a health management role in the home with little preparation, suggesting that the "medical or health home" is, in reality, the home of the person with chronic care needs

Increased demands and budget cuts for home and community-based services place more responsibilities and economic burdens on families.

In fiscal year (FY) 2010, more than half of the states reported increased demands for home and community-based services (HCBS), such as home-delivered meals and transportation, that help older people and their family caregivers live in their homes and communities. Services specifically for caregivers, including respite care, a strategy designed to give families a break from providing constant care, also were in greater demand.⁷⁶ Since the economic downturn began in late 2007, local Area Agencies on Aging (AAAs) have received a 67 percent increase in requests for caregiver support services.⁷⁷ In one survey, more than one in three (36 percent) caregivers reported that government agencies and nonprofit organizations are now less able to provide services to their relative or friend because of budget cuts.⁷⁸

The national economy remains a prolonged concern not only for state and local agencies that administer HCBS,

but also for America's families—those who receive care and those who provide the care. In FY 2010, 31 states cut non-Medicaid aging and disability services programs, and an estimated 28 states were expecting to reduce HCBS programs in FY 2011, directly impacting the availability of vital community services and supports to unpaid family caregivers.⁷⁹

Trends suggest future reliance on fewer family caregivers.

The convergence of several trends raises concerns about greater strain placed on already overburdened families in the future. Americans are living longer today than in the past with multiple, chronic health conditions and greater rates of disability in old age, including those at the highest levels of disability. Increasingly, they are living in the community, not in institutions. Disability levels of older adults living in the community continue to increase, as does the age of their family caregivers. 81

Changes in family structure, such as delayed marriage and childbirth, high rates of divorce, and smaller family size. mean that the burden of care will fall on fewer people in a family. There also are increasing numbers of childless women. Nearly 20 percent of older women do not have children today, compared to just 10 percent in the 1970s.82 Women's increased participation in the workplace, growing from 33 percent of the labor force in 1960 to 47 percent in 2009, more widely dispersed families and greater long-distance caregiving, and the shortage of direct care workers to help families provide hands-on care in the home may also reduce the availability of caregivers for the growing numbers of older people in the future.⁸³

The shift in public policy toward more HCBS and away from nursing home care—which is what most individuals with chronic conditions and disabilities want—paradoxically also contributes to an increasing reliance on potentially fewer family and friends with competing demands to provide care at home. Without families' unpaid contributions, the health and LTSS systems would be overwhelmed by the increasing need for supportive services.⁸⁴

Supporting Family Caregivers: Emerging Practice and Research

The movement toward personand family-centered care calls for identifying and addressing family needs, and integrating family caregivers as partners in care.

Person-centered care is an approach to health care and LTSS that addresses the individual's needs, goals, values, and preferences. It includes the person as an integral part of the care team, and evaluates the care and services being delivered through the eyes of the person receiving that care. This approach also recognizes, respects, and involves the person's family caregivers, as appropriate, in the planning and delivery of health care and LTSS.

As the consumer movement toward "person" (or "patient" in medical terms) and family-centered care has developed, the need to address the individual and family experience of care has gained attention in recent years. 85 Because

We can expect to see more adult children in their 60s or 70s with chronic conditions of their own, caring for a parent age 90 years and older.

serious illness and chronic disability affect the individual as well as the family, including both the person in need of care and the family caregiver as full partners in care and decision making, and improving their care experience, are viewed as important measures of personcentered care.⁸⁶

The needs of family caregivers as part of the older adult's care plan are rarely recognized and addressed in general clinical practice in health care, or in publicly funded HCBS programs to provide LTSS. Yet ignoring family needs can place caregivers at risk for negative health consequences that can jeopardize their ability to provide care in the home. Interventions that include an explicit focus on assessing the needs. strengths, values, and preferences of family caregivers are important. Such interventions can be designed to reduce burdens and health risks that can impede a caregiver's ability to provide care, prevent unnecessary hospitalizations, and prevent or delay institutional care. Strategies to strengthen and sustain caregiving families will enable them to continue as caregivers, and will reduce costs.

It is now established that both the person with chronic illness or disability and the family caregiver need to be better integrated, along with direct care workers, into the health care and LTSS teams.⁸⁷ In a person- *and* family-centered care system, family caregivers are no longer viewed as just a "resource" for their loved one; rather, they are partners on the care team, and also recognized as individuals who may themselves need training and support.

Interventions that focus on the needs and preferences of family caregivers during care transitions show positive results, including reduced hospital readmissions, better patient outcomes in functional status, and improved quality of life. 88 Involving family caregivers in discharge

planning during transitions from hospital to home may not only improve quality of care but may also help to prevent hospital readmissions among Medicare beneficiaries.⁸⁹

New models of cultural competency embrace person- and family-centered care.

The concept of cultural competency has received heightened attention in recent vears because of the forecasted need for more service providers to care for an increasingly diverse aging population and support their family caregivers. New models of care that use principles of cultural competency suggest acknowledging race and ethnicity, sexual orientation, and regional variations in culture across the country. Another key principle embraces person- and familycentered care, focusing on the older adult's concept of home, interactions with family members, the concept of team-based care and enhanced communication skills, and the awareness of his or her own culture.90

Consumer-directed services at home are an important service and funding option for families.

Consumer-directed services (also known as "participant-directed" and "self-directed") have emerged as an important, flexible, and cost-effective model in Medicaid and state-funded HCBS. This model offers older people and adults with disabilities more control over their LTSS in the home by allowing them to manage a personal care budget; hire their own workers, including their family and friends, to provide personal assistance; and purchase other needed goods and services, such as transportation.⁹¹

A national evaluation of this service delivery approach found significantly higher consumer and family satisfaction, less physical strain experienced by family caregivers, and higher quality of care as compared to those who used the traditional model of receiving home care through agencies. ⁹² Promising research suggests that new consumer-directed options that permit nurses to delegate health maintenance tasks to direct care workers in the home under their supervision can reduce family caregiver stress and improve well-being. ⁹³

Some evidence-based caregiver interventions show promise.

The unpaid contributions of family caregivers to the person being cared for and to society are huge. Yet the health risks and financial hardships that may accompany the caregiving role are substantial and well documented. Thus, there is strong interest in improving family caregivers' experiences and outcomes, which may include helping to delay or prevent nursing home use or unnecessary hospitalizations of the care recipient.

For dementia caregivers, growing consensus suggests that more comprehensive and multicomponent interventions are needed. Such interventions must be individually tailored to meet the specific goals, values, and preferences of both family caregivers and the person being cared for—after individual in-home assessment of the caregiver and care recipient. Programs that provide a combination of education, skills training, coping techniques, and counseling show positive results, but more research is needed, especially on interventions targeted to families caring for loved ones with multiple chronic conditions.

A recent review of interventions for caregivers of cancer patients found significant, positive effects on multiple outcomes. Caregivers reported significantly less burden and fewer informational needs, increased ability to cope, and improved quality of life, including better physical functioning. These interventions, like those targeting

dementia caregivers who often have the most demanding caregiving situations, appear to produce more prepared, less strained caregivers, which, in turn, is likely to benefit the person they care for.⁹⁴

Involving family caregivers in a meaningful and practical way, and supporting their own care needs, should be a key component in all new models of care that aim to integrate primary health care and LTSS to promote better care, improve the experience of care for both the person and the family, and reduce costs.

Caregiving Gains Recognition among Policymakers, Health Professionals

Family caregiving is now recognized as a central part of health care and LTSS owing to a number of converging factors: the aging of the population, the increasing prevalence and costs of multiple chronic conditions, the movement toward meaningful personand family-centered care, critical shortages in the direct care workforce, and the trend to shift the balance of LTSS away from institutional care to more HCBS, which is what most older adults and people with disabilities want.

The past decade has witnessed an increase in both policy initiatives to bolster support services for family caregivers and in professional recognition of family caregivers as partners in care. Although some observers contend that families are on their own to a greater degree today than in the past, 95 caregiving is now embedded in several key initiatives, such as the following:

Federal Level

The year 2011 is designated The Year of the Family Caregiver by the U.S. Administration on Aging to

commemorate the tenth anniversary of the National Family Caregiver Support Program (NFCSP). 6 The NFCSP, established in 2000 under the Older Americans Act, recognizes family caregivers as consumers in their own right, and provides grants to states to fund services and supports that assist family and friends to care for their loved ones at home 97

- The new health care law of 2010, the Affordable Care Act (P.L.111-148), promotes the central importance of person- and family-centered care in the design and delivery of new models of care to improve the quality and efficiency of health care, including assessment of the family caregiver's experience of care. The law explicitly mentions the term "caregiver" 46 times and "family caregiver" 11 times.
- The Caregivers and Veterans Omnibus Health Services Act of 2010 (P.L.111-163) creates, through the Department of Veterans Affairs, an important new system of comprehensive support for caregivers of veterans of wars since September 11, 2001, and a program of general caregiver support services for family caregivers of all veterans. This new comprehensive initiative, providing cash assistance, counseling, and other help for caregivers, could serve as a model for other federal and state caregiver support programs.98
- The White House Task Force on the Middle Class, created to identify and address the economic challenges facing the American middle class in light of the economic downturn, promotes initiatives to help middleclass families balance work and family caregiving responsibilities, and to provide support services for

families caring for aging relatives or people with disabilities.⁹⁹

State Level

- A forthcoming state "scorecard" offers a framework for a highperforming LTSS system across multiple components, including the recognition of and support for family caregivers as a key component of state systems of LTSS.¹⁰⁰
- In 2009, Texas enacted a law directing the state to identify family caregivers during the process in which adults apply for Medicaid HCBS, and to refer eligible caregivers for services through the state's AAAs. The law also calls for developing a standardized caregiver assessment and protocol to identify needs and appropriate services for caregivers who access services through the state's AAAs, funded under the Older Americans Act's NFCSP 101
- In 2002, California passed the nation's first paid family leave program. The law provides up to six weeks of partial pay for eligible employees who need time off from work to bond with a new child or to care for a seriously ill family member. California's landmark law was followed in 2009 by legislation establishing paid family leave in New Jersey. 102

Health Professional Practices

At the landmark National Consensus Development Conference for Caregiver Assessment, held in San Francisco in 2005, leaders and stakeholders in a range of professional and policy arenas reached consensus on the importance of systematically assessing a caregiver's own needs in health care and in the community. The fundamental principles and practice guidelines are applicable to a range

- of professionals in a variety of settings. 103
- In 2008, the American College of Physicians, along with ten other professional medical societies, endorsed ethical guidance to heighten physician awareness of the importance and complexity of the patient-caregiver-physician relationship, and to consider quality of life for both the patient and the family caregiver. 104
- Created in 2008, Next Step in Care: Family Caregivers and Health Care Professionals Working Together is a United Hospital Fund initiative to improve the quality of care transitions to and from hospitals, nursing homes, and home care agencies by regularly recognizing, training, and supporting family caregivers. 105
- Social workers, nurses, family caregiver advocates, and other experts in family caregiving met in 2008 for a groundbreaking State of the Science symposium to identify the knowledge and skills that social workers and nurses need to support caregivers of older adults. The meeting proceedings were published and widely disseminated in both *The American Journal of Nursing* and *The Journal of Social Work Education*. ¹⁰⁶
- In 2010, the National Association of Social Workers (NASW), in partnership with the AARP Foundation, developed NASW Standards for Social Work Practice with Family Caregivers of Older Adults. The standards address support for family caregivers across a range of care settings. 107
- Beginning in 2010, the AARP Foundation is partnering with NICHE (Nurses Improving Care for Health System Elders) and The American Journal of Nursing

to develop evidence-based tools to provide nurses with additional skills for supporting family caregivers of older adults in hospital settings.¹⁰⁸

These initiatives are promising but modest steps to ensure that family caregivers are recognized for their vital unpaid contributions to health care and LTSS, and to promote ways to better support and sustain families in their caregiving role.

Taking Care of Caregivers: Recommendations

Family support is a key driver in remaining in one's home and in the community, but it is not without substantial costs to the caregivers themselves, to their families, and to society. The 2009 estimate of the value of family caregiving is conservative because it does not quantify the physical, emotional, and financial costs of care. Investing sufficient resources to lessen the strain in the daily lives of caregiving families will vield a positive return on investment and help to contain health and LTSS costs by delaying or preventing the use of nursing home care, hospital inpatient care, and unnecessary rehospitalizations. Providing better and more meaningful supports for family caregivers is the right thing to do. It is essential to the well-being of our system of LTSS, our health care system, our economy, our workplaces, our families, and ourselves.

If family caregivers were no longer available, the economic cost of health care and LTSS would increase astronomically. The following policy recommendations could all be implemented at small fractions of the value of unpaid caregivers' contributions:

- Implement "family-friendly" workplace policies that include flextime and telecommuting, referral to supportive services in the community, and caregiver support programs in the workplace.
- Recognize and assess family caregivers' own needs as part of a person- and family-centered care plan—such as through publicly funded HCBS programs, hospital discharge planning, chronic care coordination and care transitions programs, and other new models of care under the Affordable Care Act—and provide or refer caregivers to supportive services.
- Make improvements to the Family and Medical Leave Act (FMLA), such as expanding coverage to protect more workers and for longer periods, and expanding its scope to cover all primary caregivers, regardless of family relationship.¹⁰⁹ Provide paid leave to permit working caregivers to care for an ill child, spouse, or parent. In addition, employers should be required to provide employees with a reasonable number of paid sick days to care for themselves or a loved one.
- Expand funding for the National Family Caregiver Support Program (NFCSP). The total NFCSP funding level, including the funding for Native American Caregiver Support, is \$160 million for FY 2011. This represents less than 1/28 of 1 percent of the economic value of caregivers' contributions. 110
- Provide adequate funding for respite programs, including the Lifespan Respite Care Act, which

- is inadequately funded at only \$2.5 million in FY 2011. Lifespan respite programs assist caregivers in gaining access to needed respite services, train and recruit respite workers and volunteers, and enhance coordinated systems of community-based respite services.
- Provide financial assistance for family caregivers to help ease some of the financial costs of caregiving. Many of these caregivers would still bear high costs associated with caregiving, including lost wages and employment benefits, lower retirement benefits, poorer health status, and higher medical expenses of their own.
- Consider reforms that protect and, if possible, improve Social Security benefits for family caregivers who must leave the workforce for caregiving responsibilities. People who disrupt their careers for full-time caregiving responsibilities can lose substantial benefits and retirement security.
- Promote new models of care that are person- and family-centered, integrate primary health care and LTSS for people with multiple chronic conditions and functional limitations, involve family caregivers as partners in care and assess their specific needs and preferences, and incorporate explicit caregiver supports into care plans to improve the effectiveness and outcomes of chronic care management.
- Promote expansion of consumerdirected models in publicly funded HCBS programs that permit payment of family caregivers. Such models allow consumers and their families to choose and direct the types of services and supports that best meet their needs.
- Encourage primary care providers and other health professionals

to routinely identify Medicare beneficiaries who are family caregivers as part of Medicare's annual wellness visit to better track the beneficiary's health status and potential risks from caregiving, including physical strain, emotional stress, and depression. Consider appropriate opportunities to help support family caregivers of Medicare beneficiaries, as this can impact the health and well-being of current and future Medicare beneficiaries.

- Encourage nurses, social workers, and other health professionals to integrate family caregivers into the care team, engage them as partners in care, and develop tools that provide greater support to family caregivers.
- Promote standard definitions of family caregiving in federally funded and other national and state surveys to better characterize the size, scope, tasks, and outcomes of family caregiving in the United States.
- Promote research to (1) identify the health tasks performed by family caregivers in order to develop measures of health management tasks to modernize federally funded surveys on LTSS and caregiving; and (2) better understand and improve the quality of interactions between family caregivers and health professionals, including better tools to track the caregiver's experience of care.

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Endnotes

- ¹The term *family caregiver* is broadly defined and refers to any relative, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance for, an older adult or an adult with chronic or disabling conditions.
- ² National Alliance for Caregiving (NAC) and AARP, *Caregiving in the U.S. 2009* (Bethesda, MD: NAC, and Washington, DC: AARP, November 2009). Funded by the MetLife Foundation.
- ³ S. Eiken, K. Sredl, B. Burwell, and L. Gold, *Medicaid Long Term Care Expenditures FY 2009* (Cambridge, MA: Thomson Reuters, 2010). http://www.hcbs.org/moreInfo.php/doc/3325.
- ⁴ J. Kasten, S. Eiken, and B. Burwell, *Medicaid Managed Long-Term Services and Supports Expenditures*. (Cambridge, MA: Thomson Reuters, 2011), http://www.hcbs.org/moreInfo.php/doc/3584.
- ⁵C. O'Shaughnessy, "National Spending for Long-Term Services and Supports (LTSS)," *National Health Policy Forum*, March 15, 2011.
- ⁶ Forbes.com, *Special Report: The Global* 2000, http://www.forbes.com/lists/2010/18/global-2000-10_The-Global-2000_Sales.html. Sales figures are actually for the most recent 12 months, as of spring 2010.
- ⁷ Centers for Medicare and Medicaid Services, 2010 Medicare Trustees Report. https://www.cms. gov/ReportsTrustFunds/downloads/tr2010.pdf.
- ⁸ U.S. Census Bureau, *Population Estimates Program, Annual Estimates of the Resident Population for the United States, Regions, States, and Puerto Rico: April 1, 2000 to July 1, 2009* (NST-EST2009-01), http://www.census.gov/popest/states/NST-ann-est.html.
- ⁹U.S. Department of Commerce, Bureau of Economic Analysis, NIPA table 1.1.5, 2009-A. http://www.bea.gov/national/nipaweb/TableView. asp?SelectedTable=5&ViewSeries=NO&Java= no&Request3Place=N&3Place=N&From View=YES&Freq=Year&FirstYear=2009&Last Year=2009&3Place=N&Update=Update&Java Box=no#Mid
- ¹⁰The World Bank, http://data.worldbank.org/indicator/NY.GDP.MKTP.CD? Accessed May 4, 2011.
- ¹¹ M. J. Gibson and A. Houser, *Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving*, AARP Public Policy Institute Brief IB-82 (Washington, DC: AARP, June 2007); and A. Houser and M. J. Gibson,

- Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update, AARP Public Policy Institute Insight on the Issues 13 (Washington, DC: AARP, November 2008).
- ¹² Mitchell LaPlante and colleagues found that the value of unpaid personal assistance provided to adults with disabilities ages 18 and older approached \$168 billion in 1996, compared with the value of paid formal assistance in the home of \$32 billion. In 1997, Peter Arno and colleagues estimated the national economic value of informal caregiving to be \$196 billion, compared with \$32 billion for paid home care in that year. The Congressional Budget Office (CBO) adjusted this estimate for inflation to \$218 billion in 2004 dollars. An updated estimate by Arno was \$306 billion in 2004. See M. LaPlante, C. Harrington, and T. Kang, "Estimating paid and unpaid hours of personal assistance services in activities of daily living provided to adults at home," Health Services Research 37, no. 2 (2002):397-413; P. S. Arno, C. Levine, and M. Memmott, "The economic value of informal caregiving," Health Affairs 18, no. 2 (1999):182-88; D. Holtz-Eakin, "The Cost and Financing of Long-Term Care Services,' CBO Testimony before the House Subcommittee on Energy and Commerce, April 27, 2005; and P. S. Arno. "Economic Value of Informal Caregiving: 2004," presented at the Care Coordination & Caregiver Forum, Department of Veterans Affairs, National Institutes of Health, Bethesda, MD, January 25-27, 2006.
- ¹³ Deloitte, *The Hidden Cost of U.S. Health Care for Consumers* (Washington, DC: Deloitte Center for Health Solutions, and New York, NY: Deloitte Center for Financial Services, 2011), http://www.deloitte.com/view/en_US/us/Industries/health-care-providers/center-for-health-solutions/health-care-consumerism/06674e83ab3ce210VgnVCM 1000001a56f00aRCRD.htm.
- ¹⁴The Deloitte definition is based on an analysis of the 2006 Health and Retirement Study (HRS), which includes care for six ADLs and six IADLs (notably not including transportation, the service most commonly provided by family caregivers). In addition, unlike the Behavioral Risk Factor and Surveillance Survey and *Caregiving in the U.S.* study, the HRS computes hours from the responses of care recipients or proxies, and thus time invested by caregivers that is not direct interaction with the care recipient is likely to be excluded.
- ¹⁵V. Molyneaux, S. Butchard, J. Simpson, and C. Murray, "Reconsidering the term 'carer': A critique of the universal adoption of the term 'carer," *Aging and Society* 31 (2011):422–37.

- ¹⁶ Family Caregiving and Public Policy: Principles for Change. 2003. http://www.caregiving.org/data/principles04.pdf, Accessed April 18, 2011.
- ¹⁷U.S. Census Bureau, *Statistical Abstract of the United States: 2011*. Table 102: Expectation of Life at Birth, 1970–2007, and Projections 2010 to 2020 (Washington, DC: U.S. Census Bureau, 2010).
- ¹⁸ Pew Research Center, *Social and Demographic Trends: The Decline of Marriage and Rise of New Families* (Washington, DC: Pew Research Center, November 18, 2010).
- ¹⁹R. C. Talley and J. E. Crews, "Framing the public health of caregiving," *American Journal of Public Health* 97 (2007):224–29.
- ²⁰ AARP Public Policy Institute, *Beyond 50.09: Chronic Care: A Call to Action for Health Reform* (Washington, DC: AARP Public Policy Institute, 2009).
- ²¹ The Lewin Group, *Individuals Living in the Community with Chronic Conditions and Functional Limitations: A Closer Look* (Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, January 2010).
- ²²D. Lawrence, "My mother and the medical care ad-hoc-race." *Health Affairs* 22, no. 2 (2003):238–42.
- ²³ See C. Levine, D. Halper, A. Peist, and D. Gould, "Bridging troubled waters: Family caregivers, transitions, and long-term care," *Health Affairs* 29, no. 1 (2010):116–24; AARP Public Policy Institute, *Beyond 50.09*; E. A. Coleman, "Falling through the cracks. Challenges and opportunities for improving transitional care for persons with continuous complex care needs," *Journal of the American Geriatrics Society* 51, no. 4 (2003):549–55; and J. L. Wolff, "Supporting and sustaining the family caregiver workforce for older Americans," unpublished paper, August 17, 2007.
- ²⁴ J. L. Wolff and D. L. Roter, "Hidden in plain sight: Medical visit companions as a resource for vulnerable older adults," *Archives of Internal Medicine* 168, no. 3 (2008):1409–415.
- ²⁵ AARP Public Policy Institute analysis of the 2009 National Household Travel Survey, Version 2.1.
- ²⁶ K. Donelan, C. A. Hill, C. Hoffman, K. Scoles, P. H. Feldman, C. Levine, et al., "Challenged to care: Informal caregivers in a changing health system," *Health Affairs* 21, no. 4 (2002):222–31.
- ²⁷ See NAC and AARP, *Caregiving in the U.S. 2009*; K. Donelan et al., "Challenged to care: Informal caregivers in a changing health

- system," *Health Affairs* 21 no. 4 (2002):222–31; and Wolff, "Supporting and sustaining the family caregiver workforce."
- ²⁸ S. H. Zarit, N. K. Orr, and J. M. Zarit, *The Hidden Victims of Alzheimer's Disease: Families under Stress* (New York, NY: New York University Press, 1985).
- ²⁹NAC and AARP, Caregiving in the U.S. 2009.
- ³⁰ Evercare and the National Alliance for Caregiving, *The Economic Downturn and Its Impact on Family Caregiving: Report of Findings* (Minnetonka, MN: Evercare, and Bethesda, MD: NAC, 2009). This study, unlike the Evercare and NAC study conducted in 2007 that focused on family caregivers of persons age 50 and older, examined the experiences of caregivers providing care to an ill or disabled relative or friend age 18 years or older. To qualify as a caregiver, the respondent had to report having helped the care recipient with at least one ADL or IADL.
- ³¹Caring.com, Usage and Attitude Survey (Caring.com, February 2011), http://www.caring.com/about/news-room/family-caregivers-face-major-financial-burdens-increased-stress-and-work-struggles.html. An online survey of family caregivers conducted in November 2010; 959 respondents.
- ³² U. Ranji and A. Salganicoff, *Women's Health Care Chartbook: Key Findings from the Kaiser Women's Health Survey* (Menlo Park, CA: The Henry J. Kaiser Family Foundation, May 2011).
- ³³ Caring.com. Usage and Attitude Survey.
- ³⁴ Evercare and NAC, Family Caregivers—What They Spend, What They Sacrifice; The Personal Financial Toll of Caring for a Loved One (Minnetonka, MN: Evercare, and Bethesda, MD: NAC, 2007).
- ³⁵NAC and AARP. *Caregiving in the U.S.* 2009.
- 36 Ibid.
- ³⁷R. Johnson and A. Lo Sasso, "The impact of elder care on women's labor supply," *Inquiry* 43 (2006):195–210.
- ³⁸ E. K. Pavalko and K. A. Henderson, "Combining care work and paid work: Do workplace policies make a difference?" *Research on Aging* 28, no. 3 (2006):359–74.
- ³⁹ MetLife Mature Market Institute, *The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents* (Westport, CT: MetLife Mature Market Institute, 2011). These estimates are based on an analysis of the 2008 panel of

respondents with a living parent from the Health and Retirement Study (HRS) that surveys adults over the age of 50, and prior research examining the impact of caregiving on caregivers' wages, Social Security savings, and retirement income. The study was restricted to family caregivers of at least one aging parent.

- 40 Ibid.
- ⁴¹C. Wakabayashi and K. M. Donato, "Does caregiving increase poverty among women in later life? Evidence from the Health and Retirement Survey," *Journal of Health and Social Behavior* 47, no. 3 (2006):258–74.
- ⁴² Evercare and NAC. *The Economic Downturn and Its Impact on Family Caregiving.*
- ⁴³ Caring.com, Usage and Attitude Survey.
- ⁴⁴ K. Aumann, E. Galinsky, K. Sakai, M. Brown, and J. T. Bond, *The Elder Care Study: Everyday Realities and Wishes for Change* (New York, NY: Families and Work Institute, October 2010). Research findings were drawn from the 2008 National Study of the Changing Workforce, a nationally representative ongoing survey of employed people in the United States conducted by the Families and Work Institute. The sample of 3,502 workers included 1,589 people who said they were "providing special attention or care for a relative age 65 and older." The sample was weighted to 2007 Census Bureau data for the total U.S. population.
- ⁴⁵ MetLife Mature Market Institute and NAC, *MetLife Caregiving Study: Productivity Losses to U.S. Business* (Westport, CT: MetLife Mature Market Institute, and Bethesda, MD: NAC, 2006). The lost productivity estimates are based on the 2004 survey of U.S. caregivers conducted by NAC and AARP, *Caregiving in the U.S. 2004*.
- ⁴⁶MetLife Mature Market Institute, NAC, and University of Pittsburgh, *MetLife Study of Working Caregivers and Employer Health Care Costs* (Westport, CT: MetLife Mature Market Institute, February 2010). Data used in this case study came from analysis of responses from 17,097 employees of a major multinational corporation who completed health risk assessment questionnaires between 2000 and 2007. The employees reside in 20 states. About 12 percent of the company's U.S. employees responded "yes" to the question, "Are you responsible for taking care of an elderly relative or friend?" Cost estimates were derived from 2007 data.
- ⁴⁷ See M. Pinquart and S. Sorensen, "Differences between caregivers and non-caregivers in psychological health and physical health: A meta-analysis," *Psychology and Aging* 18

- (2003):250–67; P. P. Vitaliano, J. Zhang, and J. M. Scanlon, "Is caregiving hazardous to one's physical health? A meta-analysis," *Psychological Bulletin* 129, no. 6(2003):946–72; and R. Schulz and P. R. Sherwood, "Physical and mental health effects of family caregiving," *American Journal of Nursing* 108, no. 9, Supplement (September 2008):23–7.
- ⁴⁸ Caring.com, 2011 Usage and Attitude Survey.
- ⁴⁹ S. H. Zarit, "Assessment of family caregivers: A research perspective," In *Caregiver Assessment: Voices and Views from the Field: Report from a National Consensus Development Conference, Vol. II*, edited by the Family Caregiver Alliance. (San Francisco, CA: Family Caregiver Alliance, 2006), pp. 113–37.
- ⁵⁰ See NAC and AARP, *Caregiving in the U.S.* 2009; M. Pinquart and S. Sorensen, "Correlates of physical health of informal caregivers: A meta-analysis" *Journal of Gerontology: Psychological Sciences* 62B (2007):126–37; and Ranji and Salganicoff, *Women's Health Care Chartbook.*
- ⁵¹ S. L. Lee, G. A. Colditz, L. F. Berkman, and I. Kawachi, "Caregiving and risk of coronary heart disease in U.S. women: A prospective study" *Annals of Preventive Medicine* 24 (2003):113–19.
- ⁵² See C. C. Cannuscio, J. Jones, I. Kawachi, G. A. Colditz, I. Berkman, and E. Rimm, "Reverberation of family illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study," *American Journal of Public Health* 92 (2002):1305–11; and F. Sparrengerger, F. T. Cichelero, A. M. Ascoli, et al., "Does psychosocial stress cause hypertension? A systematic review of observational studies," *Journal of Human Hypertension* 23 (2009):12–19.
- ⁵³ W. E. Haley, D. L. Roth, G. Howard, and M. M. Safford, "Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers: Differential effects by race and sex," *Stroke* 41 (2010):331–36.
- ⁵⁴ J. K. Glaser, K. J. Preacher, R. C. MacCulom, C. Atkinson, W. B. Malarkey, and R. Glaser, "Chronic stress and age-related increases in the proinflammatory cytokine IL-6," *Proceedings of the National Academy of Sciences Online* 100 (2003):9090–95.
- ⁵⁵ J. K. Kiecolt-Glaser, P. Marucha, S. Gravenstein, et al., "Slowing of wound healing by psychological distress," *Lancet* 346 (1995):1194–96.
- ⁵⁶ Vitaliano, Zhang, and Scanlon, "Is caregiving hazardous to one's physical health?"

- ⁵⁷ See M. M. Bishop, J. L. Beaumont, E. A Hahn, et al., "Late effects of cancer and hematopietic stem-cell transplantation on spouses or partners compared with survivors and survivor-matched controls," *Journal of Clinical Oncology* 25 (2007):1403–11; and J. K. Kiecolt-Glaser, J. R. Dura, C. E. Speicher, et al., "Spousal caregivers of dementia victims: Longitudinal changes in immunity and health," *Psychosomatic Medicine* 53 (1991):345–62.
- ⁵⁸ E. C Clipp and L. K. George, "Psychotropic drug use among caregivers of patients with dementia," *Journal of the American Geriatrics Society* 38 (1990):227–35.
- ⁵⁹ See R. Schulz and S. Beach, "Caregiving as a risk factor for mortality: The caregiver health effects study," *Journal of the American Medical Association* 282, no. 22 (1999):2215–19; N. A. Chritakis and P. D. Allison, "Mortality after the hospitalization of a spouse," *New England Journal of Medicine* 354 (2006):719–30; and L. Fredman, J. A. Cauley, M. Hochberg, K. E. Ensrud, and G. Doros, "Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of caregiver study of osteoperotic fractures," *Journal of the American Geriatrics Society* 58 (2010):937–43.
- 60 See R. Schulz, A. T. O'Brien, J. Bookwala, and K. Fleissner, "Psychiatric and physical morbidity effects of Alzheimer's disease caregiving: Prevalence, correlates and causes," The Gerontologist 35 (1995):771–91; Pinquart and Sorensen, "Differences between caregivers and non-caregivers"; Vitaliano, Zhang, and Scanlon, "Is caregiving hazardous to one's physical health?"; Kiecolt-Glaser, Dura, Speicher, et al., "Spousal caregivers of dementia victims"; R. A. Beeson, "Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses," Archives of Psychiatric Nursing 17 (2003):135–43; Schulz and Beach, "Caregiving as a risk factor for mortality"; and M. C. Norton et al., "Greater risk of dementia when spouse has dementia? The Cache County Study," Journal of the American Geriatrics Society 58 (2010):895-900.
- ⁶¹ C. C. Schubert, M. Callahan, C. M. Perkins, A. J. Hui, and H. C. Hendrie, "Acute care utilization by dementia caregivers within urban primary care practices," *Journal of General Internal Medicine* 23, no. 11 (2008):1736–40.
- ⁶² See R. Blieszner, K. A. Roberto, K. L. Wilcox, E. J. Barham, and B. L. Winston, "Dimensions of ambiguous loss in couples coping with mild cognitive impairments," *Family Relations* 56 (2007):195–208; J. Triantafillou et al., *Informal Care in the Long-Term Care System: European*

- Overview Paper (Athens/Vienna: INTERLINKS, May 2010); and Levine, Halper, Peist, and Gould, "Bridging troubled waters."
- ⁶³ E. A. Miller, S. M. Allen, and V. Mor, "Commentary: Navigating the labyrinth of long-term care: Shoring up informal caregiving in a home- and community-based world," *Journal of Aging and Social Policy* 21 (2009):1–16.
- ⁶⁴NAC and AARP, Caregiving in the U.S. 2009.
- ⁶⁵ See E. Miller and W. Weissert, "Predicting elderly people's risk for nursing home placement, hospitalization, functional impairment, and mortality: A synthesis," *Medical Care Research Review* 57, no. 3 (September 2000):259–97; and B. C. Spillman and S. K. Long, "Does high caregiver stress predict nursing home entry?" *Inquiry* 46 (2009):140–61.
- ⁶⁶ Wolff, "Supporting and sustaining the family caregiver workforce for older Americans."
- ⁶⁷ P. Doty, "The evolving balance of formal and informal, institutional and non-institutional long-term care for older Americans: A thirty-year perspective," *Public Policy & Aging Report* 20, no. 1 (2010):3–9.
- ⁶⁸ A. Houser, M. J. Gibson, and D. Redfoot. Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community: Data from the National Long-Term Care Survey, AARP Public Policy Institute Research Report 2010-09 (Washington, DC: AARP, September, 2010).
- ⁶⁹ See Doty, "The evolving balance of formal and informal, institutional and non-institutional long-term care for older Americans"; and Houser, Gibson, and Redfoot, *Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community.*
- ⁷⁰ Spillman and Long, "Does high caregiver stress predict nursing home entry?"
- ⁷¹Levine, Halper, Peist, and Gould, "Bridging troubled waters."
- ⁷² G. Sharma, K. E. Fletcher, D. Zhang, Y. Fang Kuo, J. L. Freeman, and J. S. Goodwin, "Continuity of outpatient and inpatient care by primary care physicians for hospitalized older adults," *Journal of the American Medical Association* 301, no. 16 (April 2009):1671–80.
- ⁷³ J. L. Wolff and D. L. Roter, "Hidden in plain sight: Medical visit companions as a resource for vulnerable older adults," *Archives of Internal Medicine* 168, no. 13(2008):1409–15.
- ⁷⁴L. Shugarman, A. Buttar, B. Fries, T. Moore, and B. Blaum, "Caregiver attitudes

- and hospitalization risk in Michigan residents receiving home- and community-based care," *Journal of the American Geriatrics Society* 50, no. 6 (June 2002):1079–85.
- ⁷⁵ K. Schwartz and C. Elman, "Identification of factors predictive of hospital readmissions for patients with heart failure," *Heart Lung* 32 no. 2 (March–April 2003):88–99.
- ⁷⁶ J. Walls et al, *Weathering the Storm: The Impact of the Great Recession on Long-Term Services and Supports*, AARP Public Policy Institute Research Report 2011–11 (Washington, DC: AARP, January 2011).
- U.S. Government Accountability Office,
 Older Americans Act: More Should Be Done
 to Measure the Extent of Unmet Needs for
 Services, GAO-11-237 (Washington, DC:
 U.S. Government Accountability Office,
 February 2011). Note: This study was conducted
 from December 2009 to February 2011.
- ⁷⁸ Evercare and NAC, *The Economic Downturn* and *Its Impact on Family Caregiving*.
- ⁷⁹ J. Walls et al., Weathering the Storm.
- ⁸⁰ D. L. Redfoot and A. Houser, More Older People with Disabilities Living in the Community: Trends from the National Long-Term Care Survey, 1984–2004, AARP Public Policy Institute Research Report 2010-08 (Washington, DC: AARP, September 2010).
- ⁸¹ Houser, Gibson, and Redfoot, *Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community.*
- ⁸² Pew Research Center, *Social and Demographic Trends*.
- ⁸³ See Institute of Medicine, *Retooling for an Aging America* (Washington, DC: The National Academies Press, 2008); Pew Research Center, *Social and Demographic Trends*; and A. Jacobsen, M. Kent, M. Lee, and M. Mather, "America's aging population," *Population Bulletin* 66, no. 1 (February 2011).
- ⁸⁴M. J. Gibson and A. Houser, *Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving* (Washington, DC: AARP Public Policy Institute, June 2007).
- ⁸⁵ B. Balik, J. Conway, L. Zipperer, and
 J. Watson, *Achieving an exceptional patient and family experience in inpatient hospital care*,
 IHI Innovations Series white paper (Cambridge: MA: Institute for Healthcare Improvement, 2011).
- ⁸⁶ K. Browne, D. Roseman, D. Shaller, and S. Edgman-Levitan, "Measuring patient experience as a strategy for improving primary care," *Health Affairs* 29, no. 5 (2010):1–5.

- ⁸⁷ Institute of Medicine, *Retooling for an Aging America*.
- ⁸⁸ See E. A. Coleman and Chalmers, "The care transitions intervention: Results of a randomized controlled trial," *Archives of Internal Medicine* 166 (2006):1822–28; and Naylor and Keating, "Transitional care."
- ⁸⁹ See I. Arbaje et al., "Post discharge environmental and socioeconomic factors and likelihood of early readmission among community-dwelling Medicare beneficiaries," *The Gerontologist* 48, no. 4 (2008):495–504; and M. D. Naylor, L. H. Aiken, E. T. Kurtzman, D. M. Olds, and K. B. Hirschman, "The importance of transitional care in achieving health reform," *Health Affairs*, 30, no. 4 (2011):746–54.
- ⁹⁰ C. Seelman, J. Suurmond, and K. Stronks, "Cultural competence: A conceptual framework for teaching and learning," *Medical Education* 43 (2009):229–37.
- ⁹¹ See L. Simon-Rusinowitz, D. M. Loughlin, K. Reuben, G. M. Garcia, and K. J. Mahoney, "The benefits of consumer-directed services for elders and their caregivers in the cash and counseling demonstration and evaluation," *Public Policy and Aging Report* 20, no. 1 (2010):27–31; and A. E. Benjamin, R. E. Matthias, K. Kietzman, and W. Furman, "Retention of paid related caregivers: Who stays and who leaves home care careers?" *The Gerontologist* 48 (2008):104–13.
- ⁹² Simon-Rusinowitz, Loughlin, Reuben, Garcia, and Mahoney, "The benefits of consumerdirected services."
- ⁹³ S. C. Reinhard, "A case for nurse delegation explores a new frontier in consumer-directed patient care," *Generations* 34, no. 4 (2011):75–81.
- ⁹⁴ See L. L. Northouse, M. C. Katapodi, L. Song, L. Zhang, and D. W. Mood, "Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials," *CA: A Cancer Journal for Clinicians* 60 (2010):317–39; and E. Goy, M. Freeman, and D. Kansagara, *A Systematic Evidence Review of Interventions for Non-Professional Caregivers of Individuals with Dementia*, Project #05-225 (Portland, OR: Department of Veterans Affairs, Evidence-Based Synthesis Program Center, 2010).
- ⁹⁵ See A. E. Scharlach, "Historical overview: Lessons from the past, challenges for the future in family caregiving," in "State of the Science: Professional Partners Supporting Family Caregivers," *American Journal of Nursing* 108, 9 supplement (September 2008); and Levine, Halper, Peist, and Gould, "Bridging troubled waters."

- ⁹⁶U.S. Administration on Aging, http://www. aoa.gov/AoARoot/AoA_Programs/HCLTC/ Caregiver/index.aspx, accessed April 11, 2011.
- 97 Ibid.
- ⁹⁸ U.S. Department of Veterans Affairs. Plan for Implementation, Public Law 111-163, "Caregivers and Veterans Omnibus Health Services Act of 2010, Title I, Caregiver Support, Section 101, Assistance and Support Services for Caregivers," http://veterans.senate.gov/upload/Caregivers_ part%201.pdf, accessed April 11, 2011.
- ⁹⁹ The White House Task Force on the Middle Class, created by President Obama in January 2009, is chaired by Vice President Biden. The task force supports a Caregiver Initiative designed to boost funding for caregiver supports and other home and community-based services, and a State Paid Family Leave Fund to spur state innovations in launching paid family leave programs. The Family and Medical Leave Act, enacted in 1993, allows workers to take unpaid time off, but most families cannot afford to use unpaid leave.
- ¹⁰⁰ S. C. Reinhard, E. Kassner, and A. Houser, "How the Affordable Care Act can help move states toward a high-performing system of long-term services and supports," *Health Affairs* 30, no. 3 (2011):447–53. The project, Toward a High-Performance Long-Term Services and Supports System, is led by the AARP Foundation and AARP, and funded by The Commonwealth Fund and the SCAN Foundation.
- ¹⁰¹ Texas Department of Aging and Disability Services, *Rider 38: Delivery of Caregiver Support Services* (August 2010), http://www.dads.state.tx.us/news_info/publications/legislative/Rider38Report-8-10.pdf, accessed May 23, 2011.
- ¹⁰² E. Applebaum and R. Milkman, *Leaves That Pay: Employer and Worker Experiences with Paid Family Leave in California* (2011). Note: The state of Washington passed a paid family leave law in 2007, but the law has never been implemented.
- ¹⁰³ Family Caregiver Alliance, Caregiver Assessment: Principles, Guidelines and Strategies for Change, report from a National Consensus Development Conference (Vol. I) (San Francisco, CA: Family Caregiver Alliance. 2006).
- ¹⁰⁴ S. Mitnick, C. Leffler, and V. Hood, "Family caregivers, patients and physicians. Ethical guidance to optimize relationships," *Journal of General Internal Medicine* (2010). doi:10.1007/s11606-009-1206-3.

- ¹⁰⁵ Levine, Halper, Peist, and Gould, "Bridging troubled waters."
- ¹⁰⁶ State of the Science: Professional Partners Supporting Family Caregivers, was held in Washington, DC, in January 2008. The project was led by the AARP Foundation and AARP with the Family Caregiver Alliance, the Council of Social Work Education, and the *American Journal of Nursing*, funded in part by grants from the John A. Hartford Foundation and the Jacob and Valeria Langeloth Foundation.
- 107 National Association of Social Workers, Standards for Social Practice with Family Caregivers of Older Adults, http://www.socialworkers.org/practice/standards/
 NASWFamilyCaregiverStandards.pdf, accessed April 20, 2011. Development of the NASW standards is part of Professional Partners Supporting Family Caregivers—Phase II, an initiative, funded by the John A. Hartford Foundation, to improve the capacity of social workers to support family caregivers, in partnership with the AARP Foundation, AARP, the U.S. Administration on Aging, the Family Caregiver Alliance, and NASW.
- ¹⁰⁸ This project is part of an initiative of the AARP Foundation, Professional Partners Supporting Diverse Family Caregivers, funded by the Jacob and Valeria Langeloth Foundation.
- ¹⁰⁹ FMLA allows individuals who work for employers with 50 or more employees to take up to 12 weeks of unpaid leave to care for themselves, a child, spouse, or a parent in the case of serious illness.
- ¹¹⁰ The administration's FY 2012 budget request includes a \$96.69 million Caregiver Initiative to expand help to family caregivers and older adults so that caregivers can better manage their multiple responsibilities and older adults can live in the community for as long as possible. A total of \$47.8 million over FY 2011-enacted levels would be provided to three caregiver support programs: The National Family Caregiver Support Program would be increased by \$38.308 million, or 25 percent; the Native American Caregiver Support Program would be increased by \$2.012 million, a 31 percent increase, and the Lifespan Respite Care Program would receive a \$7.505 million increase to a total of \$10 million. An additional \$48.865 million would be provided to home and communitybased services under the Older Americans Act.

Appendix A: Detailed Estimates, Data Sources, and Methodology

The number of caregivers and the economic value of caregiving were estimated separately at the state level, and then summed to get national estimates. At the state level, the economic value was calculated as (number of caregivers at any given time) x (hours of care per caregiver per week) x (52 weeks/year) × (economic value of one hour of family care). The rest of this section explains the data and methods used to compute these factors.

Number of Caregivers

The number of caregivers was estimated through analysis of data from two 2009 surveys: the *Caregiving in the U.S.* survey and the Behavioral Risk Factor Surveillance Survey (BRFSS). 1,2 Both surveys have information about the

prevalence of caregiving in the adult population and characteristics of both the caregiver and main care recipient; the questions that are used to identify caregivers of adults are shown in table A1. In addition, the BRFSS design and sample size allow for state-level estimates of caregiving prevalence, and the *Caregiving in the U.S.* data can be used to calculate the proportion of caregivers providing care in the past year.

Respondents to the *Caregiving in the U.S.* survey who answered "yes" were also asked if they were currently providing care (considered to be equivalent to "in the past month") and whether they provided help with any ADLs or IADLs (those who did not were dropped from the sample). A total of 11.5 percent of respondents were excluded in this way. Among those

Table A1

Questions to Identify Family Caregivers of Adults, 2009

Source	Caregiving Prevalence Question
BRFSS	People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?
Caregiving in the U.S.	In the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.

¹National Alliance for Caregiving (NAC) and AARP *Caregiving in the U.S. 2009* (Bethesda, MD: NAC; Washington, DC: AARP, November 2009). *Caregiving in the U.S.* is an in-depth survey of 1,480 caregivers, weighted to be a nationally representative sample.

The BRFSS is the world's largest telephone survey used to track data on demographics, health behavior, health outcome, and health care access from randomly dialed adults age 18+ in the United States. It consists of a core section of questions administered nationally and separate modules that states may choose to use. States may also design their own questions to include on the BRFSS. The survey is administered through state health departments with assistance from the Centers for Disease Control and Prevention (CDC). The question identifying caregivers is in the core section (see table 1). Additional questions about the care recipient and the caregiving relationship are in an optional caregiving module, which was used by the District of Columbia, Illinois, and Louisiana in 2009.

²Centers for Disease Control and Prevention, Office of Surveillance, Epidemiology, and Laboratory Services, Behavioral Risk Factor Surveillance System, http://www.cdc.gov/BRFSS/

Table A2

National Estimates of the Number of Caregivers and Number of Hours of Care Per Week, Adjusted to Common Definition, by Data Source (2009)

Source	Caregivers at Any Given Time	Caregivers at Any Time During Year	Average Hours of Care per Week
BRFSS	46.9 million ^a	68.6 million ^{a,b}	17.9°
Caregiving in U.S.	37.3 million ^d	54.6 million ^d	18.9
Average	42.1 million	61.6 million	18.4

^a Multiplied by 0.885 for consistency with Caregiving in the U.S. estimate.

remaining, 68.4 percent of caregivers of adults were currently providing care. *Caregiving in the U.S.* survey data were easily separated between those caring primarily for adults and those caring primarily for children. Among states with BRFSS data on the main care recipient, 94.4 percent were age 18 or older.

One of the reasons for widely varying estimates of the number of caregivers is inconsistency in the definition and questions used.³ In order to have consistent definitions, BRFSS estimates were multiplied by 0.944 and 0.885 to replicate the exclusion of caregivers of minor children and those not providing help with ADLs or IADLs, and divided by 0.684 to provide an estimate of the number providing care at any time during the year. Since *Caregiving in the U.S.* provided only national estimates, these were allocated to states in the same proportion as in the BRFSS data.

After these adjustments, the operational definition of "who is a caregiver" is similar between the two surveys. Although the wordings of the questions are different and the difference is likely to affect the response, both are consistent with a broad definition of caregiving to include help with ADLs, IADLs, and other needs.⁴ Thus, for the purpose of estimating the number of caregivers, the two surveys once adjusted for age of care recipient, time frame, and ADL/IADL assistance were treated as equivalent, and averaged to obtain the value of 42.1 million. See table A2 for consistent national estimates from each data source.

Hours of Care per Year

The data sources for the number of hours of care were the same as for the number of caregivers. Because state-specific data were not available for most states, a single value was used for all states. See table A2 for values from each data source.

^b BRFSS only measured caregiving in the last month (assumed equivalent to "any given time"). The number at any time during the year was determined by dividing by 0.684, the proportion of caregivers in the last 12 months currently providing care from *Caregiving in the U.S.*

^c Detailed data on number of hours of care are available only for the District of Columbia, Illinois, and Louisiana.

^d For these estimates, the prevalence of caregiving among the population age 18+ was taken from *Caregiving in the U.S.*; the population age 18+ was taken from U.S. Census Bureau population estimates, which were not available at the time of publication of that report. As a result, these numbers are about 1 percent higher than the equivalent values in the *Caregiving in the U.S.* report.

³ E. R. Giovannetti and J. Wolff, "Cross-survey differences in national estimates of numbers of caregivers of disabled older adults," *Milbank Quarterly* 88, no. 3 (2010):310–49.

⁴ One difference is that the *Caregiving in the U.S.* explicitly limits the definition to unpaid care. The number of family members paid for caregiving through participant direction in public programs is small but growing; it would account for only a fraction of the difference in the estimates of the number of caregivers between data sources. Care recipients may also compensate caregivers out of private funds—we do not know how often this occurs. Compensation of family caregivers is often well below the value of the service provided.

Economic Value per Hour

The economic value per hour was estimated at the state level as the weighted average⁵ of (1) the state minimum wage;⁶ (2) the median hourly wage of a home health aide;⁷ and (3) the private pay hourly rate to hire a home health aide.⁸ This weighted average is the same used in the previous *Valuing the Invaluable* study, and is meant to be a somewhat conservative estimate of the hourly economic value of caregivers' contributions.

Additional Economic Value Provided by Other Caregivers

The estimates of 42.1 million caregivers and \$450 billion in economic value are based on caregivers age 18 or older providing care to main care recipients age 18 or older. These values do not include caregivers or care recipients under age 18; secondary care recipients for those caregivers who help multiple family members or friends; nor caregivers who do not provide any assistance with ADLs or IADLs. For the first time in the Valuing the Invaluable series, we can estimate the additional economic value of these types of caregivers, though these estimates require some unverified assumptions and are less precise.

Caregivers with Multiple Care Recipients

About one-third of caregivers provide assistance to more than one person, and about one in ten to three or more people. In both data sources, the number of hours of care per week is for the primary care recipient only, and no information is

available for secondary care recipients. If, on average, caregivers contributed five hours per week to secondary care recipients, this would result in an additional \$50 billion in economic value.

Caregiving for Children with Special Needs

In 2009, both Caregiving in the U.S. and BRFSS collected data on caregivers of people under 18 as well as people 18 and older. However, the prevalence and definition of caregivers for people under 18 is significantly different between the sources; the BRFSS caregiving question for younger care recipients is the same as for adults, regardless of the age of the care recipient, whereas Caregiving in the U.S. uses a different screen. In addition to the significant methodological difference between surveys, it is challenging to delineate the distinction between "normal" parenting and the additional caregiving for a child with special needs, and it is therefore difficult to precisely estimate the prevalence and economic value for this caregiving population.

In *Caregiving in the U.S. 2009* survey data, about 14 percent of primary care recipients are younger than 18; in BRFSS, only 6 percent. Caregivers of children under age 18 provide more hours than caregivers of adults: about 30 hours per week (*Caregiving in the U.S.*) or more than 40 (BRFSS). Including caregiving for children with special needs in the total would add 4 to 8 million additional caregivers and another \$50 to \$100 billion to the economic value of family caregiving.

⁵ The private pay cost was given one-half weight.

⁶ Department of Labor, Wage and Hour Division, *Changes In Basic Minimum Wages In Non-Farm Employment Under State Law: Selected Years 1968 To 2011*, http://www.dol.gov/whd/state/stateMinWageHis.htm.

⁷ Bureau of Labor Statistics, *Occupational Employment Statistics, May 2009 Employment and Wage Estimates*, http://www.bls.gov/oes/oes arch.htm.

⁸ Genworth Financial, Genworth 2010 Cost of Care Study (Richmond, VA: Genworth Financial, April 2010).

⁹ NAC and AARP, Caregiving in the U.S. 2009.

Appendix B: State Variation

The most important factor in determining the number of caregivers in each state is state population. However, caregiving prevalence also varies among states, reflecting differences in the age structure of the population, rates of disability and chronic health conditions, and cultural and economic factors. There is also significant variation in economic value per hour among states. Table B1 presents estimates of the number of caregivers, economic value per hour, hours of care provided, and total economic value of caregiving in every state and the District of Columbia.

Table B2 compares the total economic value of caregiving to three measures in each state: total Medicaid spending, LTSS spending, and HCBS spending. Medicaid LTSS spending includes the high cost of nursing home care, as well as payments for home care and services provided in assisted living. State-to-state

variation in these ratios is mostly due to variation in state Medicaid spending.

Total Medicaid spending ranges from less than \$500 per capita in Nevada and Utah to more than \$2,500 per capita in New York and the District of Columbia.

States differ even more dramatically in Medicaid spending for LTSS, from about \$125 to more than \$1,000 per capita, and in spending for HCBS, from about \$60 to almost \$500 per capita.

The economic value of caregiving exceeded total Medicaid LTSS spending in all states, and was more than three times as high in 42 states.

Compared to Medicaid HCBS spending, the economic value of family caregiving was at least twice as high in all states, and more than six times as high in 40 states.

¹ S. Eiken, K. Sredl, B. Burwell, and L. Gold, *Medicaid Long Term Care Expenditures FY 2009* (Cambridge, MA: Thomson Reuters, 2010), http://www.hcbs.org/moreInfo.php/doc/3325, and J. Kasten, S. Eiken, and B. Burwell, *Medicaid Managed Long-Term Services and Supports Expenditures* (Cambridge, MA: Thomson Reuters, 2011), http://www.hcbs.org/moreInfo.php/doc/3584. In this report, LTSS and HCBS spending includes home health services.

Table B1

Number of Caregivers and the Economic Value of Caregiving, by State, 2009

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		Number of	Caregivers	Total		
			At any time	Hours	Economic	Total
	Total State	At any given	during the	of Care	Value/	Value
State	Population	time	year	(millions)	Hour	(millions)
Alabama	4,710,000	818,000	1,200,000	783	\$9.37	\$7,300
Alaska	698,000	88,000	128,000	84	\$13.10	\$1,100
Arizona	6,600,000	855,000	1,250,000	818	\$11.50	\$9,400
Arkansas	2,890,000	478,000	698,000	457	\$9.87	\$4,500
California	37,000,000	4,020,000	5,880,000	3,850	\$12.17	\$47,000
Colorado	5,020,000	576,000	843,000	551	\$11.93	\$6,600
Connecticut	3,520,000	486,000	711,000	465	\$12.50	\$5,800
Delaware	885,000	138,000	202,000	132	\$11.77	\$1,560
District of Columbia	600,000	68,000	99,000	65	\$11.70	\$760
Florida	18,500,000	2,780,000	4,060,000	2,660	\$10.88	\$29,000
Georgia	9,830,000	1,360,000	2,000,000	1,310	\$10.03	\$13,100
Hawaii	1,300,000	169,000	247,000	162	\$12.33	\$1,990
Idaho	1,550,000	210,000	307,000	201	\$10.03	\$2,000
Illinois	12,900,000	1,660,000	2,430,000	1,590	\$11.83	\$18,800
Indiana	6,420,000	916,000	1,340,000	877	\$10.70	\$9,400
Iowa	3,010,000	369,000	540,000	353	\$11.66	\$4,100
Kansas	2,820,000	414,000	605,000	396	\$10.41	\$4,100
Kentucky	4,310,000	735,000	1,080,000	704	\$10.03	\$7,100
Louisiana	4,490,000	627,000	917,000	600	\$9.53	\$5,700
Maine	1,320,000	191,000	279,000	182	\$12.50	\$2,300
Maryland	5,700,000	769,000	1,120,000	735	\$11.03	\$8,100
Massachusetts	6,590,000	858,000	1,260,000	821	\$13.33	\$10,900
Michigan	9,970,000	1,440,000	2,110,000	1,380	\$11.23	\$15,500
Minnesota	5,270,000	679,000	993,000	649	\$12.70	\$8,200
Mississippi	2,950,000	565,000	826,000	540	\$9.70	\$5,200
Missouri	5,990,000	865,000	1,270,000	828	\$10.70	\$8,900
Montana	975,000	131,000	191,000	125	\$11.16	\$1,390
Nebraska	1,800,000	219,000	320,000	210	\$10.70	\$2,200
Nevada	2,640,000	364,000	532,000	348	\$11.48	\$4,000
New Hampshire	1,320,000	183,000	268,000	175	\$12.67	\$2,200
New Jersey	8,710,000	1,190,000	1,750,000	1,140	\$11.59	\$13,200
New Mexico	2,010,000	287,000	419,000	274	\$11.25	\$3,100
New York	19,500,000	2,800,000	4,100,000	2,680	\$11.85	\$32,000
North Carolina	9,380,000	1,180,000	1,730,000	1,130	\$10.37	\$11,700
North Dakota	647,000	75,000	109,000	71	\$11.68	\$830
Ohio	11,500,000	1,660,000	2,430,000	1,590	\$11.03	\$17,500
Oklahoma	3,690,000	596,000	872,000	570	\$10.44	\$6,000
Oregon	3,830,000	463,000	678,000	443	\$12.43	\$5,500
Pennsylvania	12,600,000	1,850,000	2,700,000	1,770	\$11.27	\$19,900
Rhode Island	1,050,000	148,000	217,000	142	\$13.27	\$1,880
South Carolina	4,560,000	770,000	1,130,000	737	\$10.04	\$7,400
South Dakota	812,000	101,000	147,000	96	\$10.70	\$1,030
Tennessee	6,300,000	1,130,000	1,650,000	1,080	\$10.20	\$11,000
Texas	24,800,000	3,420,000	5,010,000	3,270	\$10.35	\$34,000
Utah	2,780,000	382,000	559,000	365	\$11.37	\$4,200
Vermont	622,000	83,000	122,000	80	\$12.37	\$990
Virginia	7,880,000	1,180,000	1,720,000	1,130	\$10.37	\$11,700
Washington	6,660,000	854,000	1,250,000	817	\$12.94	\$10,600
West Virginia	1,820,000	303,000	443,000	290	\$9.67	\$2,800
Wisconsin	5,650,000	524,000	766,000	501	\$11.49	\$5,800
Wyoming	544,000	72,000	106,000	69	\$9.87	\$680
USA	307,000,000	42,100,000	61,600,000	40,300	\$11.16	\$450,000
USA	307,000,000	42,100,000	01,000,000	40,300	\$11.10	\$ 4 30,000

Table B2
Ratio of Economic Value of Caregiving to Medicaid Spending, by State, 2009

	Ratio of Economic Value of Caregiving to						
	Total Medicaid	Medicaid LTSS	Medicaid HCBS				
State	Spending	Spending	Spending				
Alabama	1.66	5.2	16.7				
Alaska	1.03	2.9	4.4				
Arizona	1.12	6.3	9.2				
Arkansas	1.30	4.2	12.3				
California	1.25	4.1	7.2				
Colorado	1.85	4.8	8.2				
Connecticut	0.97	1.8	3.8				
Delaware	1.29	4.7	13.0				
District of Columbia	0.47	1.4	2.7				
Florida	1.91	6.8	19.3				
Georgia	1.70	6.6	17.5				
Hawaii	1.50	7.9	14.3				
Idaho	1.56	4.9	10.3				
Illinois	1.47	6.1	20.5				
Indiana	1.49	4.1	12.7				
Iowa	1.39	3.2	7.7				
Kansas	1.67	4.0	7.1				
Kentucky	1.32	5.1	15.4				
Louisiana	0.88	2.9	7.5				
Maine	0.91	3.2	5.6				
Maryland	1.21	4.3	10.3				
Massachusetts	0.87	2.9	6.2				
Michigan	1.47	6.5	18.5				
Minnesota	1.12	2.4	3.5				
Mississippi	1.37	4.4	29.3				
Missouri	1.16	4.7	10.2				
Montana	1.59	4.1	8.4				
Nebraska	1.39	3.4	8.2				
Nevada	2.89	11.9	25.4				
New Hampshire	1.67	3.9	8.9				
New Jersey	1.34	3.5	11.6				
New Mexico	0.94	3.3	3.9				
New York	0.65	1.5	3.1				
North Carolina	1.02	3.5	7.6				
North Dakota	1.41	2.3	7.7				
Ohio	1.31	3.5	9.7				
Oklahoma	1.51	5.0	11.0				
Oregon	1.50	4.2	5.7				
Pennsylvania	1.17	3.1	8.9				
Rhode Island	1.00	3.3	7.1				
South Carolina	1.45	6.3	15.1				
South Dakota	1.44	3.7	8.9				
Tennessee	1.49	5.1	12.0				
Texas	1.47	5.6	11.4				
Utah	2.54	10.7	23.4				
Vermont	0.87	3.1	4.5				
Virginia	2.02	6.0	13.2				
	1.60	4.8	7.3				
Washington	1.60	-					
West Virginia Wisconsin		3.1	7.1				
VVISCOUSIN	0.79	1.9	3.6				
Wyoming	1.30	3.2	5.5				

Spending data are from S. Eiken, K. Sredl, B. Burwell, and L. Gold, *Medicaid Long Term Care Expenditures FY 2009* (Cambridge, MA: Thomson Reuters, 2010); and J. Kasten, S. Eiken, and B. Burwell, *Medicaid Managed Long-Term Services and Supports Expenditures* (Cambridge, MA: Thomson Reuters, 2011). In these calculations, LTSS and HCBS spending includes home health services.

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