



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 2007.¹¹ Earlier estimates have shown steady growth in the economic value of family care from about \$200 billion in 1996.¹²

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 hours 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. Long-distance 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.⁵⁰ Family caregivers face chronic health problems of their own and health risks, such as heart disease,⁵¹ hypertension,⁵² stroke,⁵³ poorer immune function,⁵⁴ slower wound healing,⁵⁵ impaired self-care,⁵⁶ sleep problems and fatigue,⁵⁷ increased use of psychotropic drugs,⁵⁸ and even death among highly stressed spouse caregivers.⁵⁹

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.⁶⁰ 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.⁶¹

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."⁶⁸ 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.⁷² The presence of family members during physician visits has been shown to facilitate communication and increase patient satisfaction.⁷³

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.⁸⁰ 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 person- and 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 person-centered 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 years 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 family-centered 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 person- and 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).⁹⁶ 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 middle-class 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 high-performing 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 yield 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 consumer-directed 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

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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).

⁸⁴ M. 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 consumer-directed 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.”

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

⁹⁶ U.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 community-based 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) x (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?
<i>Caregiving in the U.S.</i>	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.

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

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.

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 ^c
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.

^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.

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.

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.⁹ 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.¹ 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

State	Total State Population	Number of Caregivers		Total Hours of Care (millions)	Economic Value/ Hour	Total Value (millions)
		At any given time	At any time during the year			
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

Table B2

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

State	Ratio of Economic Value of Caregiving to		
	Total Medicaid Spending	Medicaid LTSS Spending	Medicaid HCBS 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
Washington	1.60	4.8	7.3
West Virginia	1.15	3.1	7.1
Wisconsin	0.79	1.9	3.6
Wyoming	1.30	3.2	5.5
USA	1.25	3.8	8.2

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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March 21, 2012

Ms. Mary Ziegler, Director
Division of Regulations, Legislation, and Interpretation
Wage and Hour Division
U.S. Department of Labor
Room S-3502
200 Constitution Avenue, NW
Washington, DC 20210

Re: Application of the Fair Labor Standards Act to Domestic Service, RIN 1235-AA05

Dear Ms. Ziegler:

I. Introduction

AARP is a nonprofit, nonpartisan, organization with a membership representing people age 50 and older, dedicated to enhancing the quality of life for all as we age. Accordingly, we have several strong interests in this rulemaking: we are concerned about individual consumers¹ and their family caregivers who need access to affordable, quality long-term services and supports (LTSS); we are concerned about ensuring we have a system of LTSS that is sustainably financed and has a sufficient workforce that is capable of delivering that care to a rapidly aging population; and we are concerned about economic and retirement security for the nearly half of the direct care workforce² who are older workers.

¹ The term "patient" is used throughout the rule, regardless of whether the individual is receiving medically related home health care or receiving personal care services – help with daily activities such as eating, bathing, and dressing – that are non-medical in nature. AARP urges DOL to use the term "patient" only in a medical context, and otherwise to refer to the recipient of services as a "consumer", "individual", "recipient of services," "beneficiary," "client" or something similar.

Similarly, the term "home health care" is used throughout the proposed regulation, sometimes referring broadly to care provided at home, sometimes specifically to home health aides or home health agencies, and sometimes to home health care provided under Medicare and Medicaid. Home health care services are services covered under Medicare, Medicaid, and other coverage, yet Medicaid also covers other LTSS provided in the home that are not home health care and would be impacted by this rule. We encourage DOL to use the term "home health care" consistently throughout the rule to refer to care that is more medical in nature, and to use a different term, such as home care or personal care, when referring to assistance with daily activities that are non-medical. Home health agencies may provide both home health care and home care.

² DOL uses the term "caregiver" generally in reference to direct care workers such as a home health aide or personal care aide. Since it is common for individuals to use "caregiver" as short for "family caregiver," we suggest that DOL use the terms "direct care worker," "home care worker" or "home health aide" to differentiate home health aides, personal care aides, and others who provide care as a vocation, from family or informal caregivers. AARP is using the term "family caregiver" to refer to any relative, partner, friend, or neighbor who provides assistance to an older adult or an adult with chronic or disabling conditions. Family caregivers may live with or separately from the person receiving services; long-distance family caregivers often live far away from the consumer.

Summary of Position

AARP is pleased that the Department of Labor (DOL) released this proposed rule³ and appreciates the opportunity to comment on this proposed regulation regarding the application of the Fair Labor Standards Act (FLSA)'s protections to what has traditionally been exempt "companionship" services. As we read the proposals, there are three major components to the rulemaking. First, the definition of exempt companionship services has been narrowed. Second, the rules would require third-party employers such as agencies to pay minimum wage and overtime to their employees. Third, the rules tighten the recordkeeping requirements applicable to live-in employees (who would remain ineligible for overtime under the proposed rules if they are employed by an individual, member of the family or household, but who would be eligible for overtime if they are employed by a third-party employer) to help ensure they are paid at least minimum wage for all hours actually worked.

AARP supports the intent and general approach of this rule to help ensure most home care and home health care workers receive minimum wage and overtime pay. These workers perform very important services for older adults and their families, and it is difficult work, both physically and emotionally. It should be fairly compensated. However, AARP has some specific and important concerns, enumerated in the comments below, regarding each of the three components of the proposed rules. Certain aspects of the proposed rules are too vague or do not acknowledge the full realities of how services are arranged or provided, which could make it difficult for families to comply. Some proposals place an undue burden on consumers and family caregivers, and thus need to be changed to fit the unique circumstances of home care.

- **Narrower definition of "companionship" services** - AARP agrees that the definition of companionship services should be narrowed, and only true "fellowship and protection" services, accompanied by personal care or household services *incidental* to those companionship services, should be exempt from the FLSA. Consumers and their families who directly hire⁴ and privately pay a companion would remain exempt if they meet the requirements of the narrowed companionship exemption, but others would for the first time be considered an "employer" under the FLSA. AARP finds the requirement that incidental intimate personal care services only be "occasional" to be too vague and impractical to be helpful to consumers and their families, and the absolute disqualification for "general housework" to be overly restrictive. AARP recommends deleting the "occasional" requirement from incidental intimate personal care services, and instead recommends relying solely on the bright line provided by a threshold (percentage) for incidental services. DOL should also revise the general housework provision to specify that, if household work is incidental to exempt companionship services, and only provides *incidental* benefits to other household members, such

³ Application of the Fair Labor Standards Act to Domestic Service, Notice of Proposed Rulemaking, 76 Fed. Reg. 81190 (Dec. 27, 2011), (amending 29 C.F.R. pt. 552) [hereinafter *NPRM*].

⁴ The NPRM uses the term "consumer-directed employment" broadly to encompass direct-hire and private-pay arrangements, even including the grey market (see, e.g., *NPRM*, 81208), as well as consumer-directed care. This terminology is unnecessarily confusing. "Consumer direction" often refers to delivery models in public programs wherein services are paid for from public funds but consumers have more choice and control over how and when services are received and who provides them; often, they are permitted to hire a family member (in or outside the household) to provide those care services. Such models are clearly not the grey market. While publicly funded consumer-direction programs – an important option for consumers – have some similar characteristics to direct-hire and private-pay, AARP urges DOL to more clearly distinguish between the two, and to reserve the term "consumer-directed services" (or similar terms) in reference to publicly funded programs.

household work should be permitted within the companionship exemption and should not be an automatic disqualifier.

- **Elimination of exemption for third-party employers** - AARP agrees that third-party employers such as agencies should be required to pay minimum wage and overtime to their employees, a position AARP has previously taken in litigation on this issue. However, AARP strongly opposes the proposal to impose joint and several liability for FLSA compliance on consumers *when the worker is supplied and employed by a third-party employer such as an agency. When agencies are involved, they should be considered the sole employer.* The proposal for joint liability runs counter to the very reasons why consumers and their families seek the services of agencies in the first place, and in these situations is impractical and unwarranted.
- **Additional recordkeeping requirements for employers of live-in employees** - Long-term services and supports are qualitatively different in key respects from other domestic services, especially in cases requiring a live-in direct care worker. Consumers or their nonresident family caregivers may not be able to effectively monitor hours and wages or to keep sufficient records of hours and wages. DOL's proposed recordkeeping requirements need to be changed to reflect these real-life circumstances. Because of the particular situations that give rise to the need for round-the-clock, overnight, or live-in home care for the elderly or infirm, DOL should preserve some of the current recordkeeping rules. However, AARP agrees that live-in employees directly hired by a consumer or family caregiver, who would remain ineligible for overtime under the proposed rules, should be paid at least minimum wage for all hours actually worked.

AARP has analyzed the proposed rules through the lens of consumers and family caregivers – how the proposals will impact them and what further changes are needed – and has developed these comments to help ensure adequate LTSS for an aging population. With some essential improvements, AARP believes DOL can strike the right balance.

Background

Maintaining independence, choice and control is a paramount concern for older adults as they age. A vast majority (89%) of Americans age 50+ want to remain in their own homes as long as they can. Not only is receiving services in their homes and communities the choice of most older Americans, it is also cost effective. On average, the Medicaid program can provide home and community-based services (HCBS) to three older adults and adults with physical disabilities for the cost of serving one person in a nursing home.⁵ Family caregivers provide the overwhelming share of most types of assistance to their loved ones – from personal hands-on care to management of finances to coordinating services. In 2009, the estimated economic value of family caregivers' unpaid contributions was about \$450 billion, more than total Medicaid spending in that year, according to AARP's Public Policy Institute.⁶

Families often undertake caregiving willingly and many find it a source of deep satisfaction and meaning, but they often face physical, mental, emotional and financial challenges in their caregiving roles. When family caregivers reach a point where they can no longer provide all the care or services their loved one needs, the individual or family caregiver may decide to seek

⁵ A. Houser, W. Fox-Grage, & M. Gibson, *Across the States: Profiles of Long-Term Care and Independent Living 2009 17* (AARP PPI, 2009), available at http://assets.aarp.org/rqcenter/ill/d19105_2008_ats.pdf.

⁶ L. Feinberg, S. Reinhard, A. Houser, & R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving 2-3* (AARP PPI, 2011), available at <http://assets.aarp.org/rqcenter/ppi/ltc/i51-caregiving.pdf>.

some additional help to provide services. The direct care workforce – through an array of delivery and payment models – provides vital assistance to older adults and people with disabilities to help them live in their homes and communities and avoid institutional settings such as nursing homes. This assistance is expensive but most often far less expensive than nursing homes. Nationally, the average hourly rate for agency-supplied direct care workers was \$21 for home health aides and about \$19 for companions.⁷ Over the course of a year, the median cost amounts to 88 percent of the age 65+ consumer's median household income (national average), and that is on top of other living expenses. The equivalent national average figure for nursing home costs and household income is 241 percent.⁸

Despite the cost, the number of people needing LTSS is expected to rise after 2021, when the oldest baby boomers begin to turn 75, and will continue to rise until at least 2050, when all of the boomers reach late old age. Another factor driving increased demand for direct care workers is the continued and appropriate rebalancing of Medicaid toward more cost-efficient home and community-based services. According to the Bureau of Labor Statistics, home health aides and personal care aides are in the top half of the list of the top 30 occupations with the largest projected number of total job openings between 2010 and 2020: they are 9th and 11th on that list respectively, and together are projected to offer over 1.5 million more job openings in 2020 than in 2010.⁹

At the same time, as the demand for services increases, the number of adults in their primary caregiving years (ages 40-54) is remaining relatively stable. The result will be a dwindling supply of potential caregivers, both family caregivers and direct care workers, in relation to the numbers who need care. Already, people who can afford home care services often have difficulty locating competent, trained workers. Providers, too, face challenges with recruitment and retention of workers.¹⁰ Some studies have found turnover rates for aides ranging from 44 to 65 percent.¹¹ If aging boomers want to be able to receive services at home and the nation hopes to respond to the growing need for such care in a cost-effective manner, the workforce challenges in LTSS will need to be addressed sooner rather than later. AARP is committed to seeing that we meet those challenges.

One of the reasons for the high turnover in the direct care workforce is in part because of low wages and inadequate benefits. In 2010, home health aides earned a median wage of only \$9.56/hour, and personal care aides earned even less, \$8.79/hour.¹² As a consequence, half of

⁷ National Health Policy Forum, *National Spending for Long-Term Services and Supports (LTSS)* (Mar. 2011), available at http://www.nhpf.org/library/the-basics/Basics_LongTermServicesSupports_03-15-11.pdf. As indicated in n. 6 of this publication, the hourly rate for agency-supplied workers is about double what the workers themselves are paid, according to BLS.

⁸ S. Reinhard, E. Kassner, A. Houser, & R. Mollica, *Raising Expectations A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* 28-29 (AARP et al., Sept. 2011), available at http://www.longtermscorecard.org/~media/Files/Scorecard%20site/Report/AARP_Reinhard_Realizing_Exp_LTSS_Scorecard_REPORT_WEB_v4.pdf.

⁹ Bureau of Labor Statistics, Table 10. The 30 occupations with the largest projected number of total job openings due to growth and replacements, 2010-20 (Feb. 1, 2012), available at <http://www.bls.gov/news.release/ecopro.t10.htm>.

¹⁰ Institute of Medicine, *Retooling for an Aging America: Building the Health Care Workforce* 21 (National Academies Press, 2008) [hereinafter *Retooling for an Aging America*].

¹¹ D. Seavey & A. Marquand, *Caring in America: A Comprehensive Analysis of the Nation's Fastest-Growing Jobs: Home Health and Personal Care Aides* 69 (PHI, Dec. 2011), available at <http://www.directcareclearinghouse.org/download/caringinamerica-20111212.pdf> [hereinafter *Caring in America*].

¹² *Id.*, 53, Table 7.1. See also, *Retooling for an Aging America*, *supra* n. 10, Ch. 5.

personal care aides' households rely on some sort of public assistance.¹³ Home care needs to be competitive with other occupations vying for that labor. Direct care workers who work in nursing homes are not classified as companions and are already covered by the FLSA. If workers can earn more in institutional settings than they can in private homes, the home care industry will likely have a harder time recruiting and retaining a quality workforce. Unless these workers are adequately compensated and given training and other career opportunities, it will be difficult to attract and retain a competent, stable workforce on which consumers and family caregivers can rely.

Finally, from AARP's perspective, it is important to note this workforce is comprised mostly of older workers, almost half of whom are 45 and older. In 2008, 26% of personal care aides were age 45-54, and another 28% were age 55 and older.¹⁴ By 2018, about one-third of the direct care workforce is expected to be in that older 55+ age group.¹⁵ In addition to being older, this workforce is overwhelmingly female and disproportionately comprised of women of color. If these workers are making poverty-level wages and half are relying on public assistance while they are still in the workforce, their prospects for a secure retirement are nil. To the extent this rulemaking will improve wages for direct care workers, it will also enhance the opportunity to improve the retirement income of this older and diverse workforce.

II. Companionship Services for the Aged or Infirm (Duties of a Companion)

Currently, because of an overly broad interpretation of the FLSA's exemption for companions to the elderly and infirm, most home care workers – even those employed by agencies – are excluded from the Fair Labor Standards Act's minimum wage and overtime protections. Home health care and personal care services have been included within that exemption; even general household work has been considered exempt as long as it is incidental (constitutes 20% or less of the worker's weekly hours) to the exempt companionship services.

DoL proposes to reverse this presumption. Personal care aides and home health aides would be expressly covered under the FLSA as are other types of domestic employees. "Companions" would also receive the FLSA minimum wage and overtime protections, unless their duties meet the requirements of the companionship exemption, which the Department plans to narrow and significantly modify. The proposed definition of "companionship services" centers on the provision of *fellowship such as, reading, walks, errands, and social events* and *protection*, being present to monitor the consumer's "safety and well being." AARP agrees the companionship exemption should be narrowed to fellowship and protection.

The provision of intimate personal care and help with activities of daily living (ADLs) would *not* be exempt unless they are *both* incidental – 20% or less of the worker's weekly hours – *and* occasional, which is used as modifier and proviso for each listed example of incidental intimate personal care services. AARP also agrees that an incidental amount of intimate personal care services, including toileting and diaper changing, as well as not-so-intimate personal care services such as driving to appointments, errands, and social events, should be in the companionship exemption. We do not support excluding any of the services on the proposed list, and we do not believe this list should be an exclusive list. Incidental intimate personal care

¹³ *Caring in America*, *supra* n. 11, at 58.

¹⁴ PHI, *Older Direct-Care Workers: Key Facts and Trends 3*, Chart 2 (Apr. 2010), available at <http://www.directcareclearinghouse.org/download/PHI%20Older%20DCW%20Analysis%20April%202010.pdf>.

¹⁵ D. Seavey, *Caregivers on the Front Line: Building a Better Direct-Care Workforce*, 34 *GENERATIONS – J. of the Am. Society on Aging* 29 (Winter 2010–11), available at http://www.directcareclearinghouse.org/download/Gens_v34n4-4_Seavey.pdf.

services are appropriately defined as being performed attendant to and in conjunction with the provision of fellowship and protection. The proposed list of personal care examples is and needs to be inclusive enough to anticipate realistic situations in the provision of companionship services and should be clear enough and not too burdensome to permit compliance by consumers and their families.

In contrast, the requirement that incidental intimate personal care services must also be "occasional" is problematic. First, the "occasional" limitation is not always appropriate when one considers how fellowship is actually provided. An individual may perform duties clearly within the proposed definition of "fellowship," but the regular performance of tasks included in the definition of incidental intimate personal care services might be part and parcel of providing that fellowship. Yet, it appears the proposed definition of incidental intimate personal care services would unnecessarily disqualify the services from being included in the companionship exemption because they are not "occasional," even though they are under the 20 percent threshold. For example, if a companion takes an older adult for a walk on a regular basis (clearly within the definition of "fellowship") and assists the individual in putting on and taking off a coat before and after the walk, the assistance with the coat (dressing) would not be an occasional service, though it would clearly be incidental. Such personal care services incident to companionship, even if regular and recurring, should not prevent these services from being included within the companionship exemption.

Second, the term "occasional" is vague and open to differing interpretations. It is not defined in the proposed regulations and its meaning is only alluded to in the preamble. Since third-party employers cannot claim the companionship exemption under the notice of proposed rulemaking (NPRM), it is consumers and members of the family or household that will be trying to figure out whether the duties performed by their companion meet the companionship exemption. The use of vague, undefined, subjective terms such as "occasional" will expose individuals/families/households to an undue risk of liability and make it harder for them to comply.

We understand the impulse to require incidental intimate personal care services to be occasional, as individuals who are spending regular, *considerable* amounts of time on personal care tasks should not be included in the companionship exemption. However, the term "occasional" is too subjective to be workable for consumers, and it would unnecessarily and inappropriately disqualify services from the companionship exemption as in the above example. AARP recommends deleting the "occasional" requirement from incidental intimate personal care services, and instead we recommend relying solely on the bright line provided by a threshold (percentage) for incidental services. If DOL is concerned that deletion of the "occasional" requirement would result in abuses, it could propose an "incidental" time threshold lower than 20 percent. However, it is important to keep the definition of "incidental" as a specific percentage of time in order to make it easier for individuals or members of the family or household to determine if the exemption applies. If DOL retains the "occasional" requirement, it should provide a clearly understandable definition in the regulations themselves, and it should retain the 20 percent time threshold. We believe the removal of "occasional" would give additional flexibility to accommodate actual everyday situations.

General Household Work

The NPRM proposes that household work benefiting other members of the household, such as general housekeeping, making meals for other members of the household, or laundering clothing worn or linens used by other members of the household not be included as incidental intimate personal care services that would be exempt. DOL also proposes that household

services ordinarily performed by employees such as cooks, housekeepers, home health aides, and personal care aides not be considered exempt "companionship services" unless they are incidental to "the provision of fellowship and protection as described in paragraph (b) of this section," which discusses permissible incidental intimate personal care services. It is confusing that DOL includes personal care and home health aides in this list, and it is unclear why DOL is imposing an "incidental" condition (in (c)) on services already specified as needing to be incidental to companionship (in (b)). It appears that the proposed §552.6(c) is making a distinction between whether the household work is *solely* for the benefit of the individual receiving companionship services vs. whether it also benefits other members of the household.

This distinction raises questions about what is incidental and becomes unclear, particularly in a household where individuals in addition to the person receiving companionship services reside. For example, a companion who is providing services that fall under the companionship exemption makes some tuna salad for lunch. If some tuna salad is left over after the individual receiving companionship services has eaten lunch, and another member of the household eats this left over tuna salad, would this be considered general household work, thereby denying the companionship exemption for the week? What if an individual providing companionship services washes the sheets of the person receiving companionship services, and another person also sleeps in that bed? Some household work, such as cleaning up a spill on the floor to prevent a fall, could and should be "protection" under the companionship services definition, even if others in the household also benefit.

AARP agrees that providing general household services such as cooking a meal or doing laundry for the whole family, which significantly benefit all household members, should not be exempt. However, DOL should revise the general housework provision to specify that, if household work is incidental to exempt companionship services, i.e., that the amount of time spent falls under the "incidental" threshold, and only provides *incidental* benefits to other household members, such household work should be permitted within the companionship exemption and should not be an automatic disqualifier. In other words, whether a worker's services are covered or exempt – and whether an individual/family/household must pay overtime – should not vary from week to week only because some general household task happened to incidentally benefit another household member. Moreover, to help consumers and families to understand and comply with the rule, DOL should specify what is of incidental benefit to others, and give examples, as we have done here.

Companions as Exempt and Non-Exempt

The NPRM proposes to add "companions" to the definition of "domestic service employment," so companions would receive minimum wage and overtime unless their duties meet the requirements of the companionship exemption. The substance of the work, and not the title, controls whether or not a worker falls under the companionship exemption. The proposed regulation does not expressly state what happens if the 20 percent threshold of incidental intimate personal care services is exceeded. The preamble is much clearer: "Should the provision of these incidental services exceed 20 percent of the total hours worked in any workweek, then the exemption may not be claimed for that week and workers must be paid minimum wage and overtime."

To avoid confusion, and since it is unrealistic and overly burdensome to expect someone needing companionship services or a member of the family or household to read the preamble of a federal regulation, DOL should add a sentence to §552.3 of the regulations noting the job title does not control the legal status of the work and that the exemption is based on the tasks performed in each workweek. DOL should also revise §552.6(b) to read as follows: "The

performance of incidental intimate personal care services must not exceed 20 percent of the total hours worked in the work week in order to claim the exemption for that workweek."

Medical Care

AARP supports the proposal to exclude medical care "typically provided by personnel with specialized training" from the definition of "companionship services". Medical care that requires and is performed by trained personnel is currently excluded from the exemption and should remain so. We also agree with the proposal that "companionship services" includes reminding the person of a medical appointment or a predetermined medicinal schedule. Reminders are appropriately considered incidental intimate personal care services and necessary for protection. We would also support the inclusion of additional examples of minor health-related actions that do not require training and could be included within companionship services, such as applying a band aid to a minor cut or helping an elderly person take over-the-counter medication.

We also note, as delivery system reforms and other health care and LTSS reforms are implemented, direct care workers are more likely to be part of an interdisciplinary care team that provides person and family-centered care, working with the individual and their family caregiver at the center of the care team. In addition to the reasons outlined in the NPRM and in these comments, this team approach to care and the integration and coordination of health care and LTSS give further justification to providing minimum wage and overtime to direct care workers and valuing them as important members of the care team.

III. Third-Party Employment

The NPRM revises the regulations to deny assertion of the companionship exemption to third-party employers under any circumstances: whether the services provided fit within the newly narrowed companion services definition or not, whether the employee provides live-in services or not, and whether the individual/family/household may be considered a joint employer or not. AARP strongly agrees with denying any exemption to third-party agencies, a position AARP has long advocated¹⁶ as more in keeping with the design and intent of the FLSA and the better interpretation of the current regulatory requirement that the exemption be reserved for those who are employed in the *private home of the employer*. In AARP's view, requiring all home care and home health care agencies to pay minimum wage and overtime to *their* employees is a centrally important component of the NPRM.

The proposed regulations emphasize that the individual/family/household utilizing the domestic services may still assert the exemption, but only as long as the worker qualifies as a companion under the new, narrower definition. Because few direct care workers will do so, most consumers, in fact, will *not* be able to assert the exemption. Making the consumer responsible for FLSA compliance may be unavoidable in the situation in which an individual/family/household directly hires and pays a direct care worker, and is thus the *sole* employer.¹⁷ However, without so much as an acknowledgement of its import or even one

¹⁶ See Brief *Amici Curiae* of AARP and The Older Women's League (OWL) in Support of Respondent, *Long Island Care at Home v. Coke*, 551 U.S. 158 (2007) (No. 06-593) (on file with AARP), and *Amicus* Brief of AARP, Pennsylvania AFL-CIO, and Service Employees International Union, in Support of Appellee, *Bayada Nurses, Inc. v. Dept of Labor & Indus.*, ___ Pa. ___, 8 A.3d 866 (2010), available at http://www.aarp.org/content/dam/aarp/aarp_foundation/litigation/amicus_brief_pdfs/Bayada%20Nurses_CommonwealthofPA.pdf.

¹⁷ AARP notes that the NPRM does not address whether or the circumstances under which a direct care worker in the direct-hire, private-pay situation would be considered an employee of the consumer vs. an

sentence of a rationale, the NPRM would impose joint and several liability for FLSA compliance on consumers *when the worker is supplied and employed by a third-party employer*.

To impose such liability on the consumer or family when an agency-employer supplies the worker is manifestly inconsistent with DOL's entire discussion in the NPRM of congressional objectives and the legislative history of the 1974 amendments. The NPRM goes to great lengths to cite legislative history to the effect that Congress intended for the exemption to apply only to family members and private households – citing one Senator who could not imagine "...the housewife struggling with the paper work which would be required."¹⁸ Yet, the imposition of joint and several liability on an individual or family caregiver would cause those very consumers/family members to similarly struggle with legal compliance obligations and paperwork. DOL offers no explanation or rationale in the preamble for such an incongruous result. Nor does it cite any benefit to be gained by the imposition of liability in this situation, or weigh any such benefits against the burdens imposed on the consumer or family.

The imposition of joint and several liability in instances of joint employment with a third-party employer also runs counter to the very reasons why consumers and their families seek the services of home care agencies in the first place: they need and want someone else to screen, recruit and supervise the employees, and someone else to be responsible for compliance with labor and tax laws and to handle all the paperwork. Families remain the most important source of support to older adults with chronic illness or disability. But, family caregivers who are in the workplace, long-distance family caregivers, and family caregivers who need more help than they themselves can provide may all seek out paid care to fill the gap. According to PHI, about three-fourths of direct care workers work for agencies.¹⁹ Family members often turn to these agencies, even if it means paying more per hour, *precisely because* the agency handles all of the management, legal, and paperwork duties of an employer.

Moreover, it is wholly unclear how this imposition of joint liability would be triggered. If, for example, an agency fails to pay overtime to one of its employees, how would the consumer ever find that out or have access to the information underlying the claim of noncompliance? The consumer has no access to the agency-employer's wage and hour records. In the case of an agency-supplied home care worker who has worked 15 hours per week for three households, which two households would be considered liable for paying the regular wage and which one would be jointly and severally responsible for paying overtime? What if the consumer and agency have conflicting records of hours worked? At what point, and how, would the consumer find out they are considered a joint employer – when an agency goes bankrupt? Because this important caveat on agency responsibility and family exemption is only mentioned in one sentence in the preamble and is not addressed in the regulations at all, many unanswered logistical questions exist about how this obligation would be enforced and administered.

independent contractor. The issue of whether any worker is an employee, an independent contractor, or an employee misclassified as an independent contractor is always a factual determination, and a problem of longstanding concern to the Department and others, independent of this rulemaking. Because the determination of employee vs. independent contractor status is a factual one based on the economic realities of the relationship and cuts across all occupations, it makes sense for DOL to keep this issue separate from this rulemaking. However, if these proposed regulations are finalized, it is quite possible that an individual/family/household who directly hires and pays a home care worker may continue to be free from FLSA compliance requirements, not because the services themselves are exempt, but because the direct care worker is an independent contractor.

¹⁸ NPRM, *supra* n. 3, at 81196 (citing 120 Cong. Rec. S5269 (daily ed. Mar. 5, 1974) (statement of Sen. Fannin)).

¹⁹ PHI, *Who Are Direct Care Workers?* 2 (Feb. 2011), available at <http://www.directcareclearinghouse.org/download/NCDCW%20Fact%20Sheet-1.pdf>.

A consumer may be a joint employer in the sense of prescribing a home care worker's duties and some aspects of how the home care worker should accomplish them. The consumer can also tell the agency whether they like the worker supplied or would prefer a different worker, but they cannot hire or fire the worker. It is neither sensible nor practical to impose joint and several liability for FLSA compliance on the individual/family/household when a direct care worker is furnished and supervised by an agency. AARP strongly opposes the imposition of joint and several liability on consumers for FLSA compliance for agency-supplied employees. *When third-party employers are involved, they should be considered the sole employer.*

Two additional definitional issues concerning third-party employers merit comment. First, what constitutes an agency or third-party employer for purposes of these rules? Neither the current regulations nor the NPRM define the term "third party employer" in the context of domestic employment. Yet, as the NPRM indicates, many different kinds of agencies or entities are involved in the field of long-term services and supports, and not all should be considered third-party employers. If home care and home health care agencies are on one end of the spectrum, registries could be considered at the other end. In most cases, registries are merely sources of referrals for consumers. They may also perform basic background checks on their listed workers, but generally they do not train them, supervise them, or hire or fire them. Under such circumstances, they should not be considered third-party employers. Somewhere in between are 1) fiscal intermediaries, entities whose *raison d'être* is to handle payroll and provide legal and tax compliance services to consumers, often in connection with a consumer-directed care program financed by Medicaid or another public program, and 2) public authorities, which serve as employers-of-record in some states and also perform the duties enumerated for fiscal intermediaries. Entities such as registries and fiscal intermediaries play a valuable role in assisting consumers and their family caregivers. Whether fiscal intermediaries and public authorities should be considered third-party employers for purposes of FLSA compliance, however, will depend on the facts and the economic realities of the relationship. AARP urges, to the extent they are considered at least joint employers with the consumer, they should be considered the *sole* employer for purposes of FLSA compliance, similar to our position on third-party agencies, and for all of the same practical reasons enunciated above.

However, there is one specific scenario in which we believe DOL should apply an exception to its proposal to require all third-party employers to pay overtime. Often, public authorities or fiscal intermediaries are involved in the administration of publicly financed consumer-directed care (CDC) programs (see footnote 3). CDC programs may allow individuals who need HCBS to hire family caregivers to provide services and may permit them to provide more than 40 hours of assistance per week, assistance that is vital to keeping their loved one at home and out of an institution. Frequently, such family caregivers live with the person for whom they are providing services. Requiring the payment of overtime in these cases, merely because public authorities or fiscal intermediaries are involved in making these programs possible, could prevent family caregivers from providing more than 40 hours a week in paid care and impact the ability of the individual to remain at home. In addition, the situation of a family caregiver who lives with the person for whom they provide services is analogous to the overtime exemption DOL proposes for individuals or members of the family or household who have a live-in worker. For these reasons, in cases where all of the following criteria are met, we urge DOL *not* to require payment of overtime for more than 40 hours of work per week if: 1) the individual is receiving HCBS under a publicly financed consumer-directed program; 2) a third-party such as a public authority or a fiscal intermediary is involved in facilitating the CDC; and 3) a family caregiver *who lives with the care recipient* is being paid under the consumer-directed program to provide services for the individual.

The second definitional issue is what types of relationships to the consumer qualify as individual/family/household relationships for the purposes of asserting the exemption. AARP agrees with DOL's formulation that "family" and household members should be construed broadly to encompass any family relationships, whether or not the family member lives with the consumer; any householder regardless of relationship; and both legal guardians as well as those acting in loco parentis, who may be friends and neighbors who put themselves in the role of a family member to the extent they help hire a worker for someone in need. Such a broad formulation accurately reflects the realities of how eldercare actually happens today. All of these individuals should be able to assert the companionship exemption when it is appropriate, and none of them should be considered a third-party employer or a joint employer of a third-party-supplied worker under these regulations.

IV. Recordkeeping Requirements

Home care and home health workers who work in private households deserve the same rights to decent wages as other domestic service workers. However, it must be noted that long-term services and supports are qualitatively different in key respects from other domestic services such as housecleaning and gardening. The consumer may be very frail or ill or have cognitive impairments precluding her or him from being able to effectively monitor hours and wages or to keep sufficient records of hours and wages.²⁰ In these situations, the "employer" (person or persons who did the hiring) may not be in a position to adequately monitor or record hours actually worked because they may not live in the same home, state or even country as the care recipient. These impediments to fulfilling recordkeeping requirements are likely to be especially pronounced under circumstances in which the consumer requires services for longer hours – such as round-the-clock care or a live-in home care worker. AARP believes third-party agencies can fulfill the necessary recordkeeping requirements. However, in some situations in which an individual/family/household directly hires and privately pays a direct care worker, recordkeeping requirements must be adjusted to fit the circumstances.²¹

Live-In Employees

Currently, live-in domestic workers of all occupations are entitled to minimum wage for all hours worked, but they are not entitled to overtime. The employer and live-in worker can have a written agreement establishing standard hours and other parameters, but no record of actual hours worked is required; instead, the parties may rely on the agreement and other recordkeeping shortcuts. Further, the live-in worker can be required to record and submit their hours. The proposals contained in the NPRM would continue current policy that overtime for live-in workers is not compulsory, unless the live-in worker is supplied by a third-party employer. However, the NPRM would make several changes in the recordkeeping requirements for live-in domestic employees, including for live-in home care workers. The employer could no longer use agreements as a records substitute; they would have to keep records of actual, exact hours worked. They could no longer use the shortcut of notating adherence to or deviations from a fixed schedule. Instead, nonagency employers of live-in employees would need to keep the same kinds of records as other domestic service employers. Finally, employers of live-in employees would no longer be permitted to shift the responsibility for recordkeeping and submission of hours to the employee; that duty would rest on the employer.

²⁰ Nannies who care for small children also are not monitored by the "consumers" of their services. However, nannies are generally hired by a competent parent or other guardian who lives in the same household as the children and are able to monitor and keep records of hours and wages.

²¹ This will be especially important should the Department go forward with its "Right to Know under the Fair Labor Standards Act" rulemaking, RIN 1235-AA04, *available at* <http://www.reginfo.gov/public/do/eAgendaViewRule?pubId=201110&RIN=1235-AA04>.

Different compensation and recordkeeping rules are provided for live-in employees, presumably because they raise different issues than other types of employees, even those who provide overnight or round-the-clock services. Differences such as the provision of room and board and the presumption of there being certain times in which the live-in worker is off the clock justify some differences in the rules.

However, AARP is greatly concerned about requiring employers of live-in companions/home care workers to meet the same recordkeeping requirements as for other types of live-in employees, such as nannies. As noted above, the need for a live-in employee is usually due to the presence of serious medical issues or cognitive impairments. Where the consumer is too ill or cognitively impaired to supervise and monitor hours, or the hiring family member or other individual is not on-site to supervise/monitor hours, *which are usually the circumstances that give rise to the need for round-the-clock, overnight, or live-in home care for the elderly or infirm*, AARP believes DOL should preserve some of the current recordkeeping rules. Where a fixed schedule is set by agreement, the parties should continue to be able to presume the fixed schedule was worked unless weekly deviations are recorded. Moreover, the hiring employer should continue to be able to require the employee to record and submit hours. These changes would require DOL to withdraw the blanket proposed language in §552.110(c) and (d) excepting live-in domestic employees and to retain the provisions on recordkeeping currently applicable to live-in companions and home care workers. While we have the above concerns, we agree that live-in home care workers should be paid for all hours actually worked, in accordance with current regulations regarding what constitutes work time.

Direct-Hire/Private-Pay Arrangements

Should the proposed rules be approved, most direct-hire/private-pay arrangements would be newly covered. This coverage would not only be new to the home health and home care workers, it would also be new to the millions of individuals/family caregivers/household members who hire them. According to a new survey of service providers by the National Association for Home Care and Hospice (NAHC), a large portion of the respondents reported a majority of their services were paid for with private funds by the client/family or through a commercial insurance plan.²² In its analysis, DOL notes also the existence of a “grey market” in this area, wherein consumers directly hire and pay home care workers, often in cash, evading reporting and tax withholding requirements.²³ Making recordkeeping requirements too onerous will not only be a burden on consumers and their families, it will act as a disincentive for compliance.

The NPRM makes no mention of how these consumer-employers would be made aware of their new legal obligations or what tools, if any, would be available to assist them with recordkeeping and implementation. One of best ways to encourage compliance would be to make the new rules clear in the regulations themselves, as most consumers and their families will not have easy access to the preamble. Further, it will be absolutely critical for the Wage and Hour

²² National Association for Home Care and Hospice, *Companionship Services Exemption Survey*, Slide 7 (Jan. 23, 2012), available at <http://www.privatedutybenchmarking.com/wp-content/uploads/2012/01/2012-Companionship-Exemption-Survey-Results1.pdf> [hereinafter *NAHC Survey*].

²³ In one recent study, consumers’ lack of awareness about their legal obligations and the complexity of complying with tax laws played a key role in payroll tax evasion by employers of domestic workers. See, Catherine B. Haskins, *Household Employer Payroll Tax Evasion: An Exploration Based on IRS Data and on Interviews with Employers and Domestic Workers* (Dissertation, Univ. of Massachusetts – Amherst) (2010).

Division to provide easy-to-understand information about what the law requires, and tools such as checklists, recordkeeping forms, and sample agreements to assist consumers and their families with implementation. In this vein, AARP genuinely questions the estimate that “each family that directly hires a caregiver will spend one hour on regulatory familiarization.” Unless DOL makes an effort to raise awareness and provide adequate consumer information and assistance, we believe it will take consumers in direct-hire arrangements far longer than one hour to become familiar with all of the nuances of the companionship services definition, the potential for weekly variation, and the recordkeeping responsibilities they must assume. Moreover, unless the recordkeeping requirements are easy to implement, they could impose an additional burden on families who may already be struggling with medical care paperwork, coordinating care, obtaining support services, and other caregiving issues.

AARP strongly urges DOL to partner with other agencies in order to get information and tools into the hands of the consumers and family caregivers who need them. Older adults who require care and their family caregivers do not have much occasion to interact with DOL, but these populations do interact, for example, with Medicare or Medicaid (Centers for Medicare and Medicaid Services), or with the aging network services (Administration on Aging), or with services for people with disabilities (HHS Office on Disability), or with the National Clearinghouse for Long-Term Care Information, or with community-based organizations. In addition to offering more direct distribution channels for the recommended materials, these agencies and other entities might also be able to provide valuable insights to DOL regarding how best to convey information to consumers and family caregivers, who are not a typical audience for DOL communications.

V. Costs of the Proposed Rule

The proposed rule specifically invites comments “on the impact of the rule on Medicaid, Medicare, and the private market, including the impact on the affordability of home health and home and community-based services.” Medicare provides only limited coverage for skilled nursing facility care and some home health care services. Instead, the major public financing for LTSS comes through the federally and state-funded Medicaid program. Rising health care costs overall and the current fiscal pressures have made Medicaid a target for budget cuts. AARP is greatly concerned about preventing harmful cuts and preserving adequate funding for and access to Medicaid and other publicly-funded LTSS.

There are major differences among Medicare, Medicaid, and private payers in how they administer and pay for services. The proposed rule makes an estimate of the total cost of home health and personal care, then multiplies the total by 75 percent to get the cost of Medicare and Medicaid – with the balance being attributed to private insurance, out-of-pocket expenses, and a mix of other government programs. But this method assumes the costs of the proposed rule will play out in the same way with each of these types of payers – a highly unlikely assumption. For example, Medicare is moving to more bundled, episode-based reimbursements – so per-hour costs are not likely to play as big a role as with the other payers, even if it makes providers more conscious of labor-driven costs.

In Medicaid, workers already generally receive minimum wage and public programs rarely authorize more than 40 hours per week of home health aide or personal care aide services²⁴ for older adults, so we would not generally expect significant new costs to Medicaid for this population. To the extent that a state program had a concern about scarce Medicaid or other

²⁴ See P.K. Sonn, C.K. Ruckelshaus, & S. Leberstein, Fair Pay for Home Care Workers: Reforming the U.S. Department of Labor's Companionship Rules Under the Fair Labor Standards Act 15 (NELP, 2011), available at <http://www.nelp.org/page/-/Justice/2011/FairPayforHomeCareWorkers.pdf?nocdn=1>.

public dollars being consumed due to a need to pay overtime, and about this causing a decrease in hours of services for consumers, it seems like this concern could be addressed by hiring additional workers who could work the extra hours.²⁵ Home care agencies and the state programs that pay them may also be able to minimize any additional travel time costs (for employees traveling between clients) by more efficient scheduling, where possible. These regulatory changes may help reduce turnover, which could also help reduce or even possibly cancel out any additional costs due to paying for travel time between clients. Under DOL's economic analysis accompanying the NPRM, the proposed rule's costs are very small, between "0.06 to 0.29 percent of the total HHS and state outlays for home health care programs."²⁶

In addition to the impact on publicly financed programs, AARP is chiefly focused on the impact of this rule on the affordability of home care services for our members and older adults generally. The home care industry asserts that the majority of home care services are paid for with private funds of the family, not from public programs.²⁷ As DOL's analysis indicates, little is documented about the *direct-hire*, private-pay market. However, even assuming the industry's assertion is correct, and most *third-party* home care agencies' services are paid for from a family's private funds rather than being reimbursed from public funds, DOL suggests the cost impact on most individuals and families will not be significant. DOL points out that 16 states provide minimum wage and overtime coverage to "most home health care workers who would otherwise be excluded under the current regulations..." and five states provide minimum wage, but not overtime to home care workers. The general absence of reported problems in these states would seem to indicate that the application of minimum wage and overtime protections to home care services has not significantly raised costs. As DOL notes, one of the main reasons why overtime requirements can be less of a problem than might otherwise be surmised is because agencies, as well as private-pay consumer-employers, can avoid paying overtime by restricting hours for a worker to 40 hours/week and hiring another worker to cover the hours in excess of 40. NAHC's own survey found that, among the agencies already required to pay overtime or voluntarily paying overtime, over half experienced minimal to moderate increases in business costs.²⁸

AARP understands that some consumers and family caregivers would strongly prefer to be able to keep the same worker for more than 40 hours. These regulatory changes *would* require some consumers and their families to make a choice: they could pay overtime to keep the same worker for more than 40 hours (if the worker's duties did not meet the companionship exemption), or if they wanted to avoid overtime they could hire another worker to cover the extra hours. The specific calculus of this will vary for every consumer depending on their preferences, hours and types of assistance needed, availability of family caregivers, and other factors. The right answer for one consumer will not be the right answer for another consumer. Some consumers may prefer only one worker, whom they trust and with whom they have a long-standing relationship, to assist them with intimate personal care tasks. Others may want more than one worker who understands their needs and preferences, as well as knowing they have another worker to turn to if the scheduled worker is ill or unable to work at the scheduled time.

²⁵ See generally, D. Seavey & A. Olins, Can Home Care Companies Manage Overtime Hours? (PHI, 2012), available at <http://www.directcareclearinghouse.org/download/overtime-casestudies-20120209.pdf>.

²⁶ NPRM, *supra* n. 3, at 81245.

²⁷ Memorandum from Michaelle L. Baumert, Partner, Husch Blackwell LLP, to Janis Reyes, Asst. Chief Counsel, Small Bus. Admin. Office of Advocacy, re: Companionship Exemption – NPRM of December 27, 2011, at 3, (Jan. 30, 2012) (citing NAHC Survey, *supra* n. 22, however this study found only that 70% of agencies that elected to answer that survey report that the majority of their services are private-pay, not that the majority of all home care services are private-pay).

²⁸ NAHC Survey, *supra* n. 22, Slide 18.

The issue of continuity and quality of care is important, and there are multiple aspects to continuity of care. It is not self-evident that continuity of care suffers merely by virtue of involving more than one home care worker, though communication between home care workers and with the consumer and family caregiver is critical to ensuring continuity of care. Moreover, continuity of care entails more than simply the number of workers. Continuity means continuing attention and quality, attributes that can suffer when a worker is fatigued from working too many hours. Also, as noted above, the home care industry faces high turnover in the workforce, in part due to low wages, which detracts from continuity of care. Finally, adequate back-up systems and workers are vital, so that another worker is available when a regularly scheduled worker is unable to work. This is especially important in a direct-hire situation when there is no agency with a ready supply of workers involved.

Some have contended that if agency-supplied home care workers must be paid overtime and have their costs increase, consumers will no longer be able to afford them; and they will either opt for direct-hire arrangements or be "forced" into nursing homes. Even assuming the uncertain result that consumers would have a more difficult time affording agency-supplied services, AARP is not aware of any evidence indicating that consumers would be forced into nursing homes regardless of payer source.²⁹ Nursing homes are generally *more* expensive, not less, than home care services. On average, for instance, the Medicaid program can provide home and community-based services (HCBS) to three older adults and adults with physical disabilities for the cost of serving one person in a nursing home.

Moreover, if the requirement for overtime leads to greater rates of institutionalization (thus higher levels of spending on institutional care), one might expect higher rates of institutionalization or spending on such care in states that already require minimum wage and overtime. While there are many factors that influence state spending on HCBS vs. institutional care and there is no strong correlation between minimum wage and overtime pay requirements and expenditures in states on HCBS vs. institutional care for older adults and persons with physical disabilities, the data show that states can and have made progress with HCBS spending and still provide minimum wage and overtime protections. Of the six states that spend over 50 percent of Medicaid LTSS expenditures for older adults and adults with physical disabilities on HCBS, three of them provide minimum wage and at least some overtime protections (Washington, Minnesota, and California). Of the 10 states with the lowest percentage of Medicaid HCBS expenditures, six states have no minimum wage and overtime provisions and four states have minimum wage or minimum wage and overtime provisions for home care workers.³⁰

Given that overnight shifts often contemplate that both the consumer and the home care worker will be asleep for some or all of that shift, AARP would be open to some modification of the regulations being proposed regarding overnight shifts, however, any such modifications should be reasonable. Some have suggested that the companionship exemption be retained for overnight shifts, or that some or all of a home care worker's overnight hours not be considered work hours. These recommendations seem to go too far. Even if a worker can sleep for a few hours or read a book, an overnight shift is a shift spent away from home and with very limited ability to engage in one's normal private pursuits. They are at work. We note this situation may

²⁹ See discussion regarding treatment of third-party agencies in the context of consumer-directed care in section III *supra*.

³⁰ *Cf.*, S. Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports: 2011 Update*, Table AG, (Thompson Reuters, October 31, 2011), available at <http://www.hcbs.org/files/208/10395/2011LTSSExpenditures-final.pdf>, and *NPRM*, *supra* n. 3, Table 1-2, at 81204-81206.

also arise when a consumer or family caregiver hires a worker to travel with the consumer and provide services, such as on a vacation, if the worker is not considered a live-in worker.

DOL already has regulations on the books that address waiting time,³¹ on-call time,³² and sleep time.³³ Currently, for shifts that last less than 24 hours, all hours are considered work hours, even though the employee may sleep or engage in other personal activities when not being called to duty. Under the NPRM, it is our understanding that these regulations would now apply to night shift home care workers. Also under current regulations, for shifts of 24 hours or more, the parties are permitted to exclude an entire sleep period of eight hours, unless the sleep is interrupted to such an extent that the employee cannot get 5 hours of sleep at some point during the night. Perhaps DOL could consider applying some of the concepts in §785.22 to shifts covered by §785.21. For instance, if the overnight hours worked represent overtime hours, perhaps they could be considered work hours, but not overtime hours, assuming that sleep time was largely uninterrupted. Or the regulations could permit the parties to agree on an overnight flat rate of sufficient size to ensure that the worker is paid at least minimum wage for all shift hours. Some slight modification to account for the fact that both the consumer and the worker may be asleep for most of the shift might make the new regulations more workable for both employers and employees, and is one that DOL may wish to consider.

VI. Conclusion

In summary, the aging population, the strong preference of older adults to live at home, and the need for cost-effective and balanced state LTSS systems means a strong demand for home health aides and personal care aides now and in the future. These jobs are low-paying, offer few or no benefits, are physically and emotionally challenging, and have high turnover rates that can mean poor quality and lack of continuity of care. People performing similar jobs in nursing homes or other residential settings receive minimum wage and overtime, while home care workers do not. There should be parity across settings for the same or similar jobs.

Helping individuals live in their homes and supporting family caregivers means having a home care workforce sufficient in size, skills, and competencies available to provide the quality services that consumers and their family caregivers need. The proposed rule takes an important step by providing minimum wage and overtime to most home care workers to help ensure their availability to consumers, reduce turnover, and improve the economic security of a workforce in which older workers predominate. However, this should be done in a way that makes key changes to the proposed rules to ensure they do not place inappropriate or unnecessary burdens on consumers and their family caregivers.

As noted above, the changes made in the proposed regulations would be new to direct care workers and to millions of individuals and family caregivers. They would also be new to many third-party employers, state Medicaid programs, consumer-directed care programs, and other publicly financed programs. Because it may take some time for consumers and family caregivers to learn about what the changes would mean for them, take providers some time to prepare to comply (for instance by hiring additional staff), and take public programs some time to determine what the changes mean for them and implement them, AARP urges DOL to consider whether a reasonable transition period (e.g., a phase-in period or a grace period during which no penalties for noncompliance are assessed) might be advisable.

³¹ 29 C.F.R. §§785.14-15.

³² 29 C.F.R. §785.17.

³³ 29 C.F.R. §785.20-22.

Thank you for the opportunity to comment on these important proposed regulations and your consideration of our recommendations for ways to make the proposed rule more workable for consumers and their family caregivers. If you have any questions, please contact Deborah Chalfie at 202-434-3760 or Rhonda Richards at 202-434-3770 in our Government Affairs Department.

Sincerely,

A handwritten signature in black ink, appearing to read "David Certner", with a long horizontal flourish extending to the right.

David Certner
Legislative Counsel and Legislative Policy Director
Government Affairs

