



# NAVIGATING THE DEMANDS OF WORK AND ELDERCARE



UNITED STATES DEPARTMENT OF LABOR



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# Foreword



**By Thomas E. Perez**  
U.S. Secretary of Labor

Take a moment to picture a family caregiver. One might picture a parent, usually a mother, with a small child. But this image is just one example of the countless and varied types of unpaid and family care that happen across this country every day. As Secretary of Labor, I am committed to supporting working caregivers across the spectrum – from spouses caring for ill partners, to children supporting their own parents as they age, to moms and dads bonding with a new child. In addition to sharing these stories, I am committed to championing and advancing policies that help people address and navigate work-family challenges, both expected and unexpected.

This report focuses specifically on the challenges facing the millions of working people who provide unpaid and often informal care to elderly friends and family, and the policies we can enact to support them. While these caregivers are not always at the forefront of our minds, they play a vital role in enabling millions of seniors to continue living independently, and they help defray the costs of paid or institutional care. In fact, the economic value of informal care for elders was an estimated \$234 billion in 2011, more than institutional and community care combined, according to the Congressional Budget Office.

But this care often comes at an additional price for caregivers who are also trying to manage working outside the home – personal and professional costs that may be hard to quantify. When you find out that you're going to have a new baby, your friends may throw you a party; you know that they are there to provide support and help. Contrast that with when your mother breaks her hip or your dad gets diagnosed with Alzheimer's – you may feel alone and overwhelmed by the sudden need to provide care.

While children gradually become less reliant on their parents, aging parents often become more reliant on their children. And as the level and intensity of the care they need increases, so does the complexity. It is also difficult to predict or estimate the duration of care an older person may need. Caring for an aging loved one often includes assisting with everyday activities like monitoring finances and keeping up home maintenance, but those activities are often not covered by leave laws that focus on medical care.

These factors make eldercare uniquely challenging when trying to balance a career and other obligations, like raising one's own children. Fortunately, there are ways to support working people who are navigating these questions and hurdles.

The policies we outline in this report are not new ideas, but they are still rarities for too many working Americans. Paid family leave, paid sick time, scheduling flexibility and predictability, and protections from caregiver discrimination would all help families better weather various storms – whether financial, personal, or professional.

Some of it is common sense: When an employee knows he'll be able to bring his mom to a weekly physical therapy appointment or be with her in hospice, he's going to be less stressed and distracted on the job. These policies help keep valuable employees productive, in the workplace, earning a paycheck, and contributing to our economy. This is a win for employers, families, and our economy.

Our country is experiencing major demographic changes. So we have a choice. We can prepare for these changes by adjusting how we think about paid leave and other policies, or we can wait until the wave crashes on our loved ones, our workplaces, and ourselves. States and cities across the country are leading the effort and paving the way for federal policies. This report bolsters the case for why caregivers of the elderly also need these policies and explains how the policies can make a difference to them, their families, their communities, their employers, and our economy.

When today's working people were young, they were cared for by parents, aunts and uncles, grandparents, friends, and neighbors. Now it is our turn to provide care to ensure our loved ones' older years are defined not just by medical appointments, but also by dignity and companionship. That is the true testament to the value of family, in all senses of the word.

## Introduction and Executive Summary

*When Michael’s father had a major stroke, he needed medical care and physical assistance to accomplish tasks that had once been simple. His son stepped up – but even though he only lived 50 miles away, and even though the owners of the warehouse where he worked understood his need to miss work, the unexpected demands took a cut out of his paycheck. While some companies in the United States allow workers to accrue paid time off, Michael is one of the millions of hardworking Americans who have no paid family leave. He worked for his company for years – frequently stepping up to meet the company’s needs. But when Michael needed support, he found himself with reduced income, struggling to pay the bills and feed his family, saying “The amount of stress that I am under is affecting my ability to function on a day-to-day basis.”<sup>1</sup>*

Michael is one of millions of informal, unpaid caregivers – family, friends, and neighbors who provide intermittent or regular care to their older loved ones. They provide medical care, help with daily activities like bathing and meals, manage finances and housework, navigate the health care system, provide friendship and stimulation, and perform countless other chores and tasks. A majority (61 percent) of these caregivers are also working outside the home, most of them full-time.<sup>2</sup> This report is about people like Michael – whose valuable contributions often go unnoticed – and what we can do to support them as indispensable workers and as invaluable caregivers.\*

Much of the national discussion about policy support for caregivers has focused on parental leave and affordable childcare, and with good reason. Families with children are increasingly reliant on two breadwinners to make ends meet and support such as paid, job-protected parental leave, and childcare ensure mothers and fathers don’t need to choose between a paycheck and time with their children.

<sup>1</sup> In this report, the terms “informal caregiver,” “family caregiver,” “unpaid caregiver,” “eldercare provider,” and “working caregiver” all refer to people who are providing unpaid, nonprofessional care to elderly family members as well as elderly friends and neighbors. Where possible, we refer to data and information that looks at informal caregivers who have other employment outside the home; where this information is not available, the population described is specified. This group of caregivers does not include paid, professional home care workers, such as personal care aides or home health aides. Furthermore, the subject matter of this report is distinct from the population affected by the Final Rule: Application of the Fair Labor Standards Act to Domestic Service (Home Care Final Rule), which was finalized by the Department of Labor in 2013, and which established minimum wage and overtime protections for most paid, professional home care workers. As discussed in the Home Care Final Rule, family caregivers are in some circumstances paid for the services they provide, in which case the Final Rule applies. Such paid family care providers are not the subject of this report.

Unfortunately, the challenges working Americans face in caring for aging relatives and friends have not garnered the same attention; indeed, these informal caregivers are even referred to as the “shadow workforce.”<sup>3</sup> However, a significant demographic shift is bringing their stories to the fore. Between 1946 and 1964, the United States saw a spike in birthrates, leading to the aptly named “Baby Boom Generation.” This generation worked hard and saved up, and many are now retired or approaching the end of long careers. But many of these so-called Boomers – who number roughly 75 million<sup>4</sup> – will also need caregiving support as they grow older. And this responsibility will fall largely on the shoulders of their children, grandchildren, spouses, friends, neighbors, and other loved ones, many of whom are also working and may be supporting families of their own. Unlike previous generations, many families today do not have a non-working caregiver available to provide full-time care.<sup>5</sup>

8 However, our workplace and public policies have not evolved to meet the needs of the growing army of unpaid, mostly family, caregivers who also work outside the home. While some may work for a supportive company or sympathetic boss, too many are forced to juggle the countless and unpredictable demands on their time for years on end, often with little formal support. Some are forced to cut back on the hours they work, leave the workforce, or slip into poverty.<sup>6</sup> These impacts may be experienced disproportionately by women, who stand to gain the most from business and public policy solutions to help working caregivers balance their responsibilities and avoid these consequences.

Such policies include providing workplace flexibility, paid sick time, and paid family leave, and ensuring workers are protected from discrimination based on their family responsibilities. When tenable, workplace flexibility allows employees to adjust the time and location of their workday, enabling them to respond to caregiving needs, without taking unpaid leave. Predictable work schedules that do not change at a moment’s notice make it easier for hourly workers to plan ahead and balance work and caregiving obligations. Paid sick days allow for workers to respond to short-term and last-minute caregiving needs while paid family leave helps when workers must care for family members on a longer-term basis. Preventing family responsibilities discrimination ensures that workers aren’t penalized at work for doing what is expected of all of us – taking care of loved ones. Together, these benefits and policies provide working caregivers what they need most: time to fulfill caregiving responsibilities while maintaining their jobs, contributing to the economy, earning a living, and saving for retirement.<sup>7</sup>

In addition to enabling unpaid caregivers to continue working, work-family policies and legal protections have positive benefits for businesses and our national economy. They can increase worker productivity, improve retention, and elevate employee morale as workers continue to hold down their jobs.<sup>8</sup>

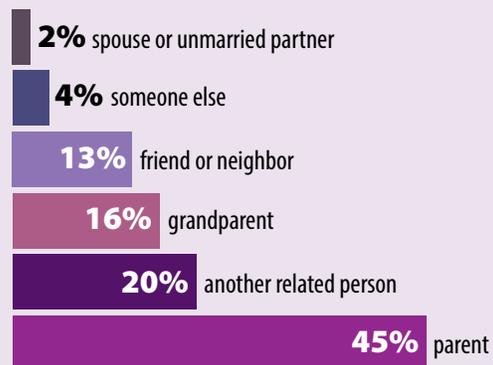
# The Growing Need for Caregiving and the Important Role of Informal Care

The first Baby Boomers reached the age of 65 in 2011, and roughly 10,000 Boomers continue to hit that milestone every day.<sup>9</sup> By 2050, the elderly population is expected to nearly double to 88 million from 48 million in 2015, when elders will make up 28 percent of the adult population.<sup>10</sup> Americans are also living longer – by 2050, over 19 million people, or one in five elders, will be age 85 and older – leaving them vulnerable to health problems and more in need of assistance.<sup>11</sup> According to the Department of Health and Human Services (HHS), 52 percent of older Americans will eventually need some form of long-term care.<sup>12</sup>

Aging Americans have multiple options for where they age and who provides necessary support, but each comes at a cost. By choice or necessity, they may end up in nursing homes, assisted living facilities, or their communities. In the United States in 2010 just over 80 percent of those who needed long-term services and support were living in the community.<sup>13</sup> These figures reflect both preferences and basic economics: Most Americans prefer to stay at home, and high-quality institutional care is expensive.

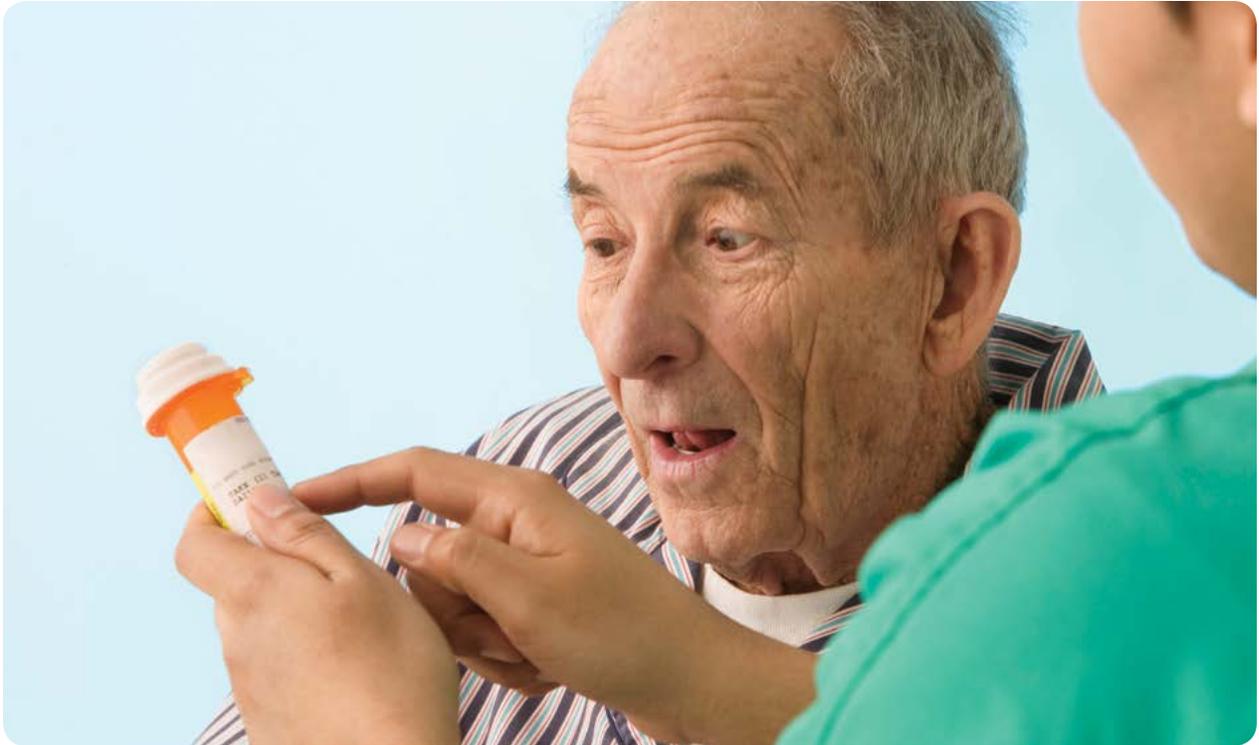
Regardless of where they live, many older Americans likely will need a great deal of informal and family support, which may include managing finances and the logistical details of assisted living for those living in institutions or providing personal hands-on care for those aging at home. Disabled elders aging at home primarily rely on family and friends to provide support, and two-thirds receive exclusively informal care.<sup>14</sup> The demand to provide informal care will be felt by many people: By one estimate, two in five adults over the age of 50 have surviving parents or parents-in-law who may require care, and one in five have surviving parents already in poor health.<sup>15</sup> Many will also be called on to care for other relatives and loved ones.

## Relationships: Who is receiving care from working, informal eldercare providers?



Note: Some caregivers provide care to multiple persons. Also, the relationship is categorized as “grandparent” only if the caregiver and the care recipient do not live together. If they live together, the relationship is categorized as “another related person.”

Source: Bureau of Labor Statistics, “Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey,” September 23, 2015, unpublished tabulations of working caregiver characteristics derived from American Time Use Survey 2013-2014; data provided to the Department by the Bureau of Labor Statistics.



The needs of aging Americans vary widely, and the support they require mirrors this variance.<sup>16</sup> Many need long-term care due to chronic health conditions like arthritis, diabetes, Alzheimer's or other forms of dementia, or as a result of a stroke. Elderly Blacks are more likely than elderly Whites to have a disability.<sup>17</sup> Others may need help with Activities of Daily Living (ADLs), including bathing, dressing, and eating, or Instrumental Activities of Daily Living (IADLs), such as preparing meals, shopping, managing money, using the telephone, doing housework, and taking medication.<sup>18</sup> Still others need help with more complex tasks such as basic medical care, medication management, and the administration and coordination of health and social services.<sup>19</sup> Family caregivers also perform nursing tasks, such as administering injections, tube feedings, and catheter and colostomy care.<sup>20</sup> Like many new parents, caregivers of the elderly often have little advance knowledge or training.<sup>21</sup>

Many elders prefer to age at home and in their communities, but they need caregivers' support to make it possible.<sup>22</sup> And many people value the opportunity to help those who cared for or raised them: their parents, grandparents, spouses, long-time friends and family members. Their contributions are also economically significant: The Congressional Budget Office estimated the economic value of informal care for elders at \$234 billion in 2011, more than institutional and community-based care combined.<sup>23</sup>

Informal assistance at home also benefits care recipients by preventing or delaying their entry into nursing homes. Furthermore, informal care has been found to shorten elders' stay in the hospital, potentially because informal caregivers can act as advocates for recipients and catch errors in medication or notify hospital staff if something goes wrong.<sup>24</sup>

## A Picture of Working, Informal Eldercare Providers

Nearly twenty-five million working people – one out of every six workers – are caregivers for an elderly person or persons age 65 or above.<sup>i</sup> (Note that eldercare is defined broadly; see main report Endnote 2.) Most working caregivers (77 percent) hold full-time jobs. A majority of these caregivers are middle aged (ages 45-64), and almost one in four is a millennial, age 15 to 34.<sup>ii</sup> More than one in four working caregivers (27.5 percent) is part of the “sandwich generation,” meaning that they simultaneously care for children and an older loved one.<sup>iii</sup> And according to a recent NAC/AARP survey looking more broadly at caregivers of all persons age 50 and above, Hispanic caregivers spend more time providing care each week than White caregivers (32 versus 21 hours), and Hispanic and Black caregivers are much more likely to provide care at the equivalent of full-time (41 hours or more each week) than are White caregivers.<sup>iv</sup>

Working men and women are caregivers in roughly equal numbers (12.0 million men and 12.7 million women).<sup>v</sup> Among working caregivers, women are more likely than working men to provide daily care (16.0 percent versus 12.3 percent, respectively), but men are more likely to have provided eldercare for at least 10 years (19.8 percent of men versus 13.5 percent of women).<sup>vi</sup> Research also indicates that women eldercare providers (working and non-) provide more hours of care than men on average and often provide more demanding care, including direct, hands-on care, while men provide fewer hours of care on average and handle tasks that take less time, such as home maintenance.<sup>vii</sup> While nearly 70 percent of male caregivers work, just over half (55 percent) of women work.<sup>viii</sup> Like all women workers, those who are working caregivers are much more likely than men to work part-time (31 percent versus 14 percent, respectively).<sup>ix</sup>

<sup>i</sup> Bureau of Labor Statistics, “Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey,” Table 1. Number and Percent of the U.S. Population who were Eldercare Providers by Sex and Selected Statistics, Averages for the Combined Years 2013-2014, September 23, 2015, retrieved from <http://www.bls.gov/news.release/pdf/elcare.pdf>; unpublished tabulations of working caregiver characteristics derived from American Time Use Survey 2013-2014; data provided to the Department by the Bureau of Labor Statistics. Other estimates are lower: HHS estimated that 8 million informal caregivers of the elderly worked (44 percent of 18 million total caregivers); see Brenda Spillman, et al., “Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving,” April 2014, retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/77146/NHATS-IC.pdf>.

<sup>ii</sup> Bureau of Labor Statistics, “Unpaid Elder Care in the United States, 2013-2014 Data from the American Time Use Survey,” unpublished tabulations. Note that among all caregivers (working and non-), 60 percent of caregivers are women.

<sup>iii</sup> Bureau of Labor Statistics, “Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey,” unpublished tabulations.

<sup>iv</sup> National Alliance for Caregiving and AARP Public Policy Institute, “Caregivers of Older Adults: A Focused Look at Those Caring for Someone Age 50,” June 2015, retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/caregivers-of-older-adults-focused-look.pdf>.

<sup>v</sup> Bureau of Labor Statistics, “Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey,” unpublished tabulations.

<sup>vi</sup> Ibid.

<sup>vii</sup> Ann Bookman and Delia Kimble, “Families and Eldercare in the Twenty-First Century,” *Future of Children*, Fall 2011, vol. 21, no. 2, p. 124, retrieved from [http://www.futureofchildren.org/publications/docs/21\\_02\\_06.pdf](http://www.futureofchildren.org/publications/docs/21_02_06.pdf); Kerstin Aumann and others, “Working Family Caregivers of the Elderly: Everyday Realities and Wishes for Change” Families and Work Institute, 2010, p. 2; Bureau of Labor Statistics, “Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey,” Table 5.

<sup>viii</sup> Bureau of Labor Statistics, “Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey,” unpublished tabulations.

<sup>ix</sup> Ibid.

**Employed, Informal Eldercare Providers**

Description/Category	Number (in thousands)	Share of Working Caregivers
<b>Total</b>	24,693	100.0%
<b>Male</b>	11,989	48.6%
<b>Female</b>	12,704	51.4%
<b>15 to 24</b>	2,429	9.8%
<b>25 to 34</b>	2,923	11.8%
<b>35 to 44</b>	3,928	15.9%
<b>45 to 54</b>	7,933	32.1%
<b>55 to 64</b>	6,101	24.7%
<b>65 years and over</b>	1,377	5.6%
<b>Parent of Child Under 18</b>	6,800	27.5%
<b>Not a Parent of a Child Under 18</b>	17,893	72.5%
<b>White</b>	21,262	86.1%
<b>Black</b>	2,430	9.8%
<b>Hispanic<sup>1</sup></b>	2,120	8.6%
<b>Less than high school diploma<sup>2</sup></b>	709	3.2%
<b>High school graduate, no college<sup>2</sup></b>	5,990	26.9%
<b>Some college or associate degree<sup>2</sup></b>	6,372	28.6%
<b>Bachelor's degree and higher<sup>2</sup></b>	9,194	41.3%
<b>No spouse or unmarried partner present in household</b>	8,586	34.8%
<b>Spouse or unmarried partner present in household</b>	16,107	65.2%
<b>Work Full-Time</b>	19,012	77.0%
<b>Work Part-Time</b>	5,681	23.0%

Source: Bureau of Labor Statistics, "Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey," September 23, 2015, unpublished tabulations of working caregiver characteristics derived from American Time Use Survey 2013-2014; data provided to the Department by the Bureau of Labor Statistics.

<sup>1</sup> Persons of Hispanic or Latino ethnicity may be of any race.

<sup>2</sup> Note that estimates of the number of eldercare givers by educational attainment are derived looking only at individuals age 25 and above. Consequently, the shares of caregivers with each level of educational attainment are calculated as shares of working caregivers age 25 and above and not as shares of all working caregivers.

## Paid Home Care Workers: Can They Fill in the Gap?

Every day across our nation, millions of care professionals go to work caring for people in their homes – helping family caregivers who are juggling paid employment and their unpaid caregiving responsibilities as they attempt to balance both.

The demand for paid caregivers will increase as Baby Boomers hit retirement age at a moment when American life expectancy is higher than ever. In 2012, the home care aide workforce consisted of about 2 million workers – over 90 percent women and more than half women of color.<sup>i</sup>

Paid home care jobs like home health aides are among the U.S.'s fastest growing occupations. Between 2014 and 2024, employment of personal care aides and home health aides will grow by more than 800,000 jobs, and there will be over 1.1 million job openings by 2024 when replacement workers are included.<sup>ii</sup> However, low wages, scarce benefits, and lack of career advancement opportunities make it difficult to recruit and retain enough home care workers to meet this increasing demand. The typical home care worker earns approximately \$20,000 a year, often working unpredictable hours, and some work far more than 40 hours per week while many struggle to piece together full-time employment.<sup>iii</sup>

As our population ages and trends away from institutional care and toward more in-home services, it is in our collective interest to ensure a sustainable pipeline of skilled workers ready to provide the care so many of us will rely on at some point in our lives.

One critical policy development that helps to fill these jobs and make them better is the long-awaited minimum wage and overtime protections afforded to the home care workforce by the Department of Labor when it published relevant regulations in October 2013. According to the final report of the White House Conference on Aging, these “wage protections and other measures that enhance the labor standards for direct care workers are critical to efforts to recruit and retain a sufficient number into the profession to keep pace with the growing need.”<sup>iv</sup>

Public sector unions also help build this pipeline of workers by guaranteeing decent wages and adequate benefits. Labor unions help ensure that home care workers receive fair wages, workplace protections and benefits, as well as professional development and training. Those provisions help to attract more qualified workers and reduce turnover rates.<sup>v</sup>

The Labor Department also announced a forthcoming catalogue summarizing the range of career pathways programs to support entry into health care careers and the development of a Federal plan for continuing to build the evidence about promising health care career pathway programs.<sup>vi</sup>

<sup>i</sup> PHI, “Home Care Aides at a Glance,” February 2014, retrieved from <http://phinational.org/sites/phinational.org/files/phi-facts-5.pdf>.

<sup>ii</sup> Bureau of Labor Statistics, Employment Projections, “Table 1. Occupational employment and job openings data, projected 2014 and projected 2024, and worker characteristics, 2014,” retrieved from [http://www.bls.gov/emp/ep\\_table\\_107.htm](http://www.bls.gov/emp/ep_table_107.htm).

<sup>iii</sup> Bureau of Labor Statistics, Occupational Employment and Wages, May 2015, 31-1101 Home Health Aides, retrieved from <http://www.bls.gov/oes/current/oes311101.htm> and 39-9021 Personal Care Aides, retrieved from <http://www.bls.gov/oes/current/oes399021.htm>; PHI, “Home Care Aides at a Glance,” February 2014, retrieved from <http://phinational.org/sites/phinational.org/files/phi-facts-5.pdf>. Also see PHI, “Paying the Price: How Poverty Wages Undermine Home Care in America,” p. 4, retrieved from <http://phinational.org/sites/phinational.org/files/research-report/paying-the-price.pdf>; Commission on Long-Term Care, Report to the Congress, September 30, 2013, p. 18-22 retrieved from <https://www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf>.

<sup>iv</sup> White House Conference on Aging, “Final Report,” 2015, p. 4, retrieved from <https://whitehouseconferenceonaging.gov/2015-WHCOA-Final-Report.pdf>.

<sup>v</sup> Secretary Thomas Perez and Attorney General Lisa Madigan, “Taking Care of Our Caretakers,” U.S. Department of Labor Blog, July 17, 2014, retrieved from <https://blog.dol.gov/2014/07/17/taking-care-of-our-caretakers/>.

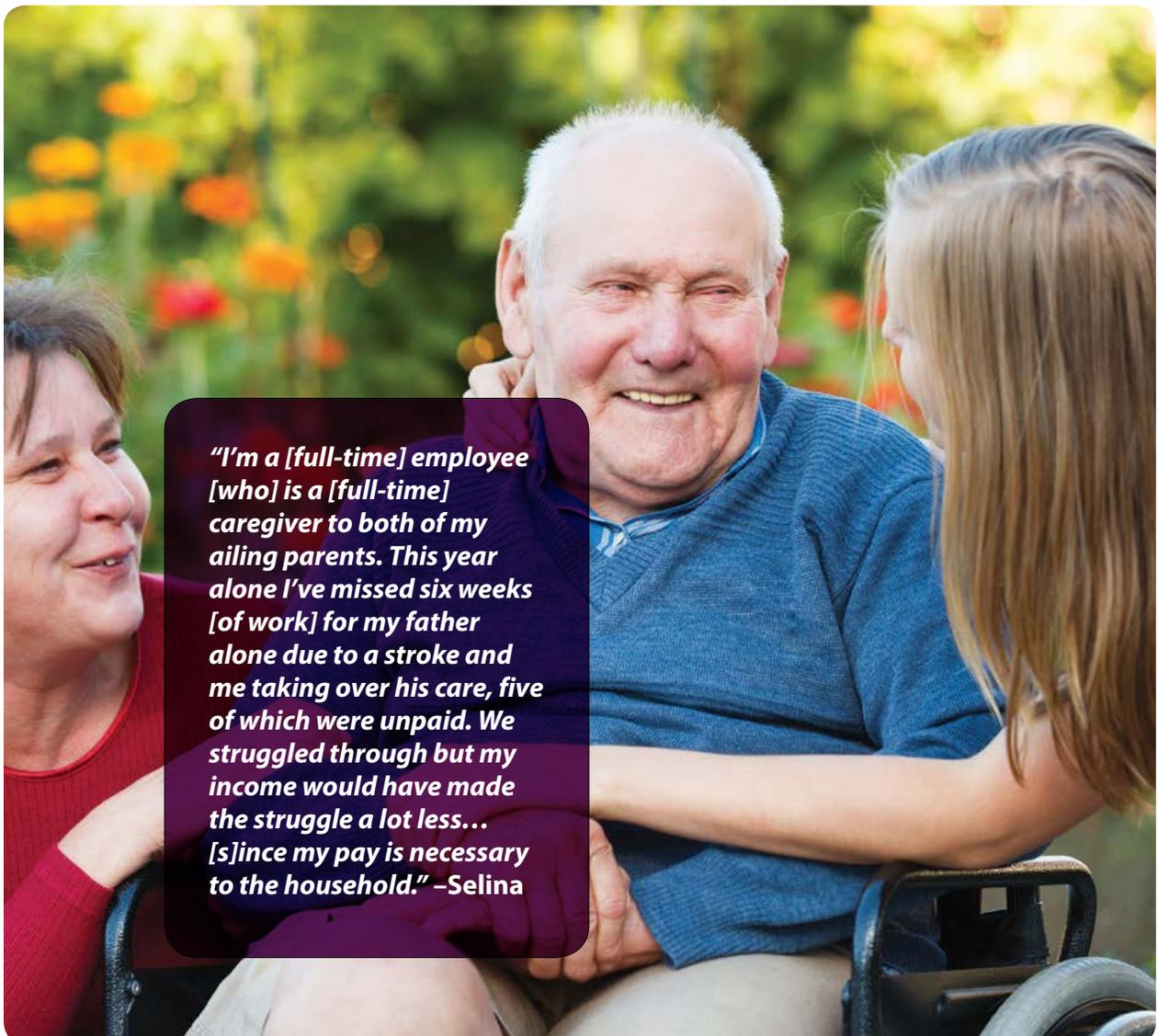
<sup>vi</sup> White House Conference on Aging, “Final Report,” p. 10.

## The Challenges of Working While Caregiving

Providing loved ones who prefer to age in their homes and communities the opportunity to do so is no doubt rewarding – but it can also be unpredictable, time-consuming, financially taxing, physically and mentally exhausting, and stressful.

These challenges are compounded for working caregivers.<sup>25</sup> The financial consequences can be substantial as workers may be inclined to turn down promotions in order to have more time for caregiving. They also may be penalized for attendance issues or compromised performance, or they may be forced to reduce hours or leave the workforce entirely. Each of these affects earnings, savings, and working general economic security.

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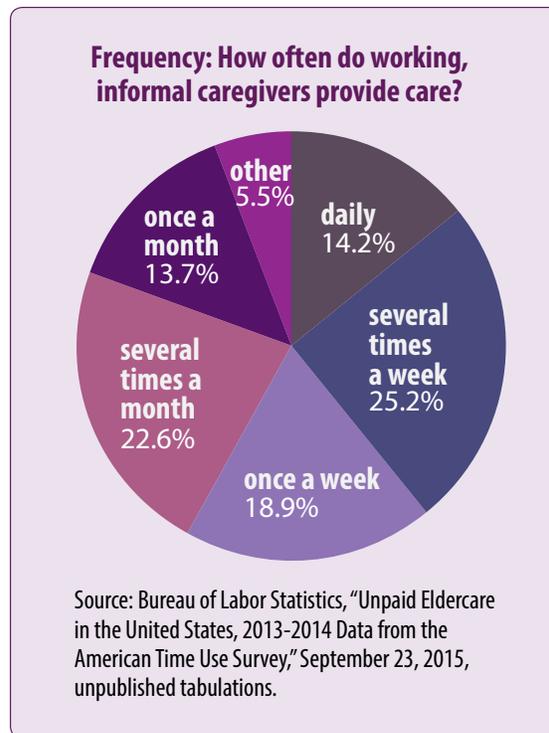
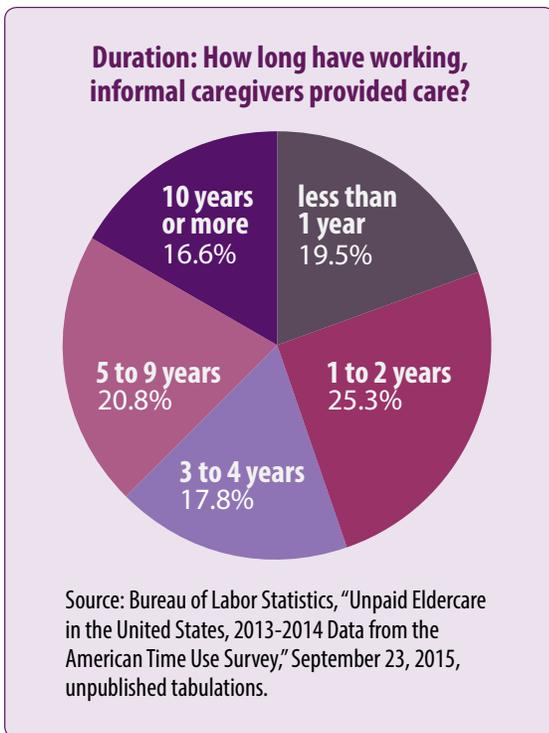


*"I'm a [full-time] employee [who] is a [full-time] caregiver to both of my ailing parents. This year alone I've missed six weeks [of work] for my father alone due to a stroke and me taking over his care, five of which were unpaid. We struggled through but my income would have made the struggle a lot less... [s]ince my pay is necessary to the household." –Selina*

## Eldercare: Unpredictable, Demanding, Stressful

Many working Americans will have to care for a child or an aging friend or family member at some point – but public attitudes towards these forms of caregiving are worlds apart. The birth or adoption of a baby is usually an eagerly awaited event, but future caregivers of the elderly may not hope for or even anticipate that role.<sup>26</sup> The need for eldercare often occurs suddenly, even as the causes may come on slowly. A parent falls and breaks a hip, or an aunt starts getting lost going to the grocery store.

Eldercare needs are unpredictable: the kind of care, duration, intensity, and frequency can all vary widely and change over time and without warning. While the need for child care generally decreases over time, the need for eldercare usually increases.<sup>27</sup> Care can last for years – among working caregivers for the elderly, more than half have provided care for three or more years (see Chart: Duration).<sup>28</sup> Also, of these caregivers, more than half (58 percent) provide care on at least a weekly basis (see Chart: Frequency), according to the BLS American Time Use Survey, and they provide an average of 53 hours of care per month, according to the National Survey of Caregiving.<sup>29</sup>



Eldercare can often be stressful which may compromise caregivers’ own health and well-being.<sup>30</sup> Stress may lead to serious health problems, such as high blood pressure, depression, diabetes, and heart disease.<sup>31</sup> According to the 2011 National Study of Caregiving, 44.4 percent of eldercare providers experience emotional difficulties and 22.9 percent experience physical difficulties due to caregiving.<sup>32</sup> In addition, one in five caregivers reports fair or poor health. While health problems cannot be definitively ascribed to caregiving, reported health problems include depression, anxiety, sleep problems, pain, weakness, low energy, and exhaustion.<sup>33</sup> These risks can be further complicated when socioeconomic factors are included. Caregivers with lower incomes and less education are more likely

to report poor health, according to a 2015 survey of caregivers of those 50 years and older by the National Alliance for Caregiving and AARP (NAC/AARP survey).<sup>34</sup>

Caregiving duties also appear to more strongly impact women's mental and physical health, potentially because women are more likely to provide care for longer hours and more regularly than men. In addition, women caregivers are more likely to provide physical or medical care as well as household work, while men are more likely to provide indirect care such as shopping, assisting with repairs, and lawn and garden maintenance.<sup>35</sup>

This stress tends to be greater when elders live with their caregivers and when these caregivers provide higher amounts of care, although caregivers who live far away have challenges as well.<sup>36</sup> They may miss work to travel to their loved one, and the level of care they are able to provide is often limited. Managing care from a distance can cause emotional strain from worrying about how loved ones are faring.<sup>37</sup>

Moreover, caregiver stress has implications for recipients of care and is a predictor of entry into nursing homes. While informal caregiving generally has been shown to prevent older Americans from entering nursing homes, if a caregiver is stressed, the likelihood that a care recipient will enter a nursing home rises.<sup>38</sup>

## Caregiving for Older Americans with Alzheimer's

The emotional, physical and financial stresses occasioned by caregiving and work-life conflict are particularly challenging if an older loved one suffers from dementia, including Alzheimer's disease. About half of caregivers for the elderly are caring for someone who probably or possibly has dementia, according to the National Study of Caregivers.<sup>i</sup> Caring for someone with dementia, especially Alzheimer's, poses special challenges, including increased levels of care and supervision. Recent polling has found that among caregivers providing care to someone age 50 or above, those caring for persons with Alzheimer's, dementia, or another form of mental confusion are particularly likely to have difficulty with helping with ADLs and medical and nursing tasks, particularly likely to experience high physical and emotional stress, and particularly likely to say caring has affected their own health for the worse.<sup>ii</sup>

Because advancing age is the main risk factor for dementia, as the population ages, the number of older Americans with dementia is projected to increase sharply. The Alzheimer's Association estimates that over five million Americans, or roughly one in ten people who are 65 and older, currently have Alzheimer's, and they project that by 2050, this number could nearly triple to 13.8 million, or even more.<sup>iii</sup>

Working caregivers for older loved ones with Alzheimer's experience a great deal of work-life conflict, including going in late or leaving early (54 percent), taking a leave of absence (15 percent), taking a less demanding job or moving from full-time to part-time work (13 percent), or even giving up work entirely (9 percent).<sup>iv</sup>

<sup>i</sup> Spillman, et al., "Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving," April 2014, p. 10, retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/77146/NHATS-IC.pdf>.

<sup>ii</sup> National Alliance for Caregiving and AARP Public Policy Institute, "Caregivers of Older Adults," p. 17.

<sup>iii</sup> Alzheimer's Association, "2016 Alzheimer's Disease Facts and Figures," 2016, p. 23, retrieved from [https://www.alz.org/documents\\_custom/2016-facts-and-figures.pdf](https://www.alz.org/documents_custom/2016-facts-and-figures.pdf).

<sup>iv</sup> *Ibid*, p. 41.

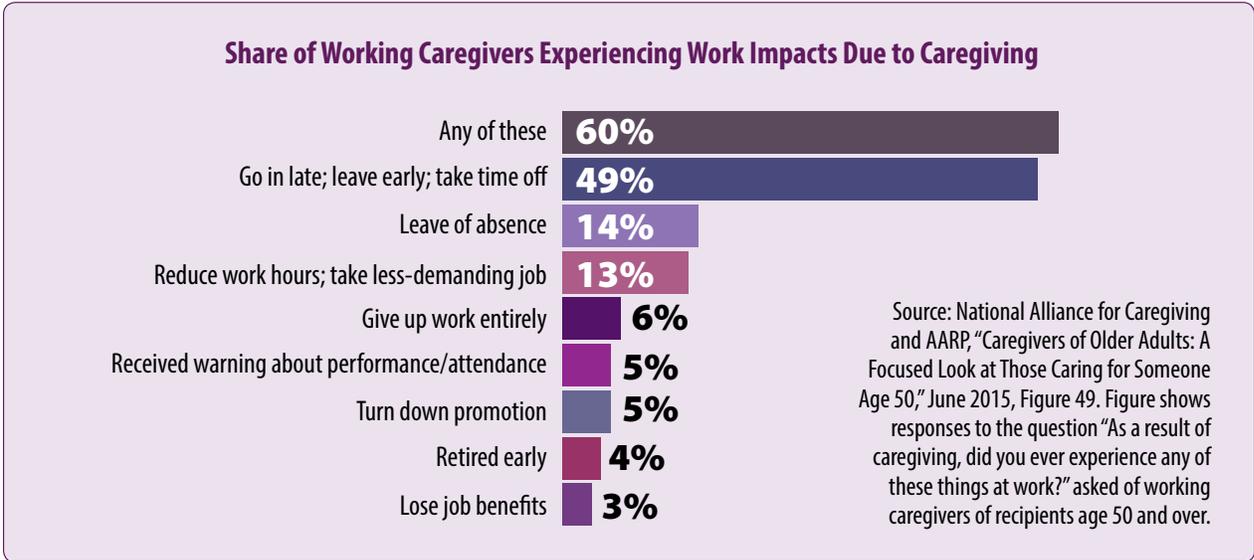


**Shannon's mom was diagnosed with brain cancer. She was a paid caregiver for another family, and she had to keep working to care for her two boys and pay her mortgage and the bills. As a result, she couldn't care for her own mom. "The time I lost with my mother is still a sad and emotional trauma that I wouldn't wish on any other person.... It's horrible enough to lose the one you love the most, but to not be able to spend quality time is even worse."**

***"My mother has had breast cancer for the last 6 years. She lives with me and is 89 years old in her final stages of life.... It breaks my heart to watch this disease slowly take her life away day by day and not be able to stay home to care and spend quality time with her before the end." – Nancy***

## Work, Interrupted

Working caregivers are frequently interrupted at work.<sup>39</sup> For those who stay at their job, caregivers face a variety of challenges (see Chart: Work Impacts). In all, among working caregivers caring for people age 50 and older, 60 percent experienced some impact at work due to caregiving, according to the NAC/AARP survey.<sup>40</sup> Many workers saw caregiving disrupt their work schedules and some had to curtail their careers.<sup>41</sup> Half (49 percent) of workers had to go in late, leave early, or take time off; 14 percent took a leave of absence; 13 percent reduced work hours; 5 percent turned down a promotion; and 5 percent even received a warning about their performance or attendance while 3 percent lost job benefits.<sup>42</sup> These impacts were greater for high-burden caregivers (as reported by survey respondents) and for caregivers who provided demanding care such as performing medical and nursing tasks.<sup>43</sup>



Studies also show that caregiving may significantly reduce workers' hours and/or labor force participation, especially for workers providing intensive caregiving.<sup>44</sup> Indeed, a 2007 survey by Evercare and the National Alliance for Caregiving of 1,000 family and friend caregivers of older adults (50 plus) who provide at least 5 hours of unpaid care in a typical week found that 37 percent of caregivers had quit their job or reduced work hours as a result of caregiving responsibilities.<sup>45</sup> This means these workers immediately suffer partial or even complete losses to their income, health insurance, and other employer-provided benefits, but they also may end up with lower Social Security and pension benefits, and may be able to contribute less to retirement savings accounts. These impacts are likely particularly harmful to women caregivers, who, some studies indicate, are more likely to drop out of the workforce and/or reduce their hours to accommodate caregiving than men.<sup>46</sup>

If eldercare providers leave the workforce to provide care but decide to return after caregiving duties have ended, they may face lower probabilities of receiving job offers; they also may face difficulties returning to full-time work if they choose to work part-time while caregiving.<sup>47</sup> And if they do find work, it may be at a lower wage.<sup>48</sup> Of those workers who retired early or left the workforce and were caring for someone age 50 or older, 38 percent said they did so to spend more time caring for a loved one, and nearly 29 percent said they did so because their employer did not offer them flexible hours.<sup>49</sup>



Vince is a full-time caregiver for his father, who has Alzheimer's. He started providing care at age 29 and continues to do so 12 years later. When his father first needed care, Vince was running his own company. However, after two and a half years, the challenge of caring for his father and operating his business became too much, so he dissolved the company. Vince considered using paid caregivers but could not afford them. At age 36, he has exhausted his retirement savings and is very concerned about his economic future. Vince recently got married and while he and his wife want to have children, they feel they cannot do so unless their financial outlook improves.<sup>50</sup>

## The Financial Costs

Working caregivers make valuable contributions to their loved ones and society as a whole, but the financial consequences are significant. Because, as discussed above, caregivers may be forced to cut back their hours or leave the labor market altogether, caregiving can have a negative impact on their current financial situation and can have a significant effect on their retirement savings and income as well.<sup>51</sup> Some caregivers fall into poverty and stay there as they themselves age.<sup>52</sup> Yet the overwhelming expenses related to caregiving, both out-of-pocket costs and loss of wages and benefits, make it even more important that caregivers retain their jobs and incomes.

The National Study of Caregiving found that 22.5 percent of caregivers for the elderly experience financial difficulties due to caregiving.<sup>53</sup> According to the NAC/AARP survey, the financial burden falls more heavily on those providing more hands-on care and care for a long period of time.<sup>54</sup> At the same time that working caregivers may have reduced income, their costs often start to climb. Out-of-pocket caregiving expenses can be very high. According to a 2016 study of caregivers, providing care for adults age 50 and older costs on average \$7,064 per year. Caring for adults with dementia is even more expensive, averaging \$10,697 per year.<sup>55</sup> An estimate by Genworth Financial, an insurance company that offers long-term care insurance, found that in 2015, out-of-pocket spending by caregivers (broadly, not just of the elderly) averaged about \$10,000 per year, an increase of over 35 percent from 2010.<sup>56</sup>

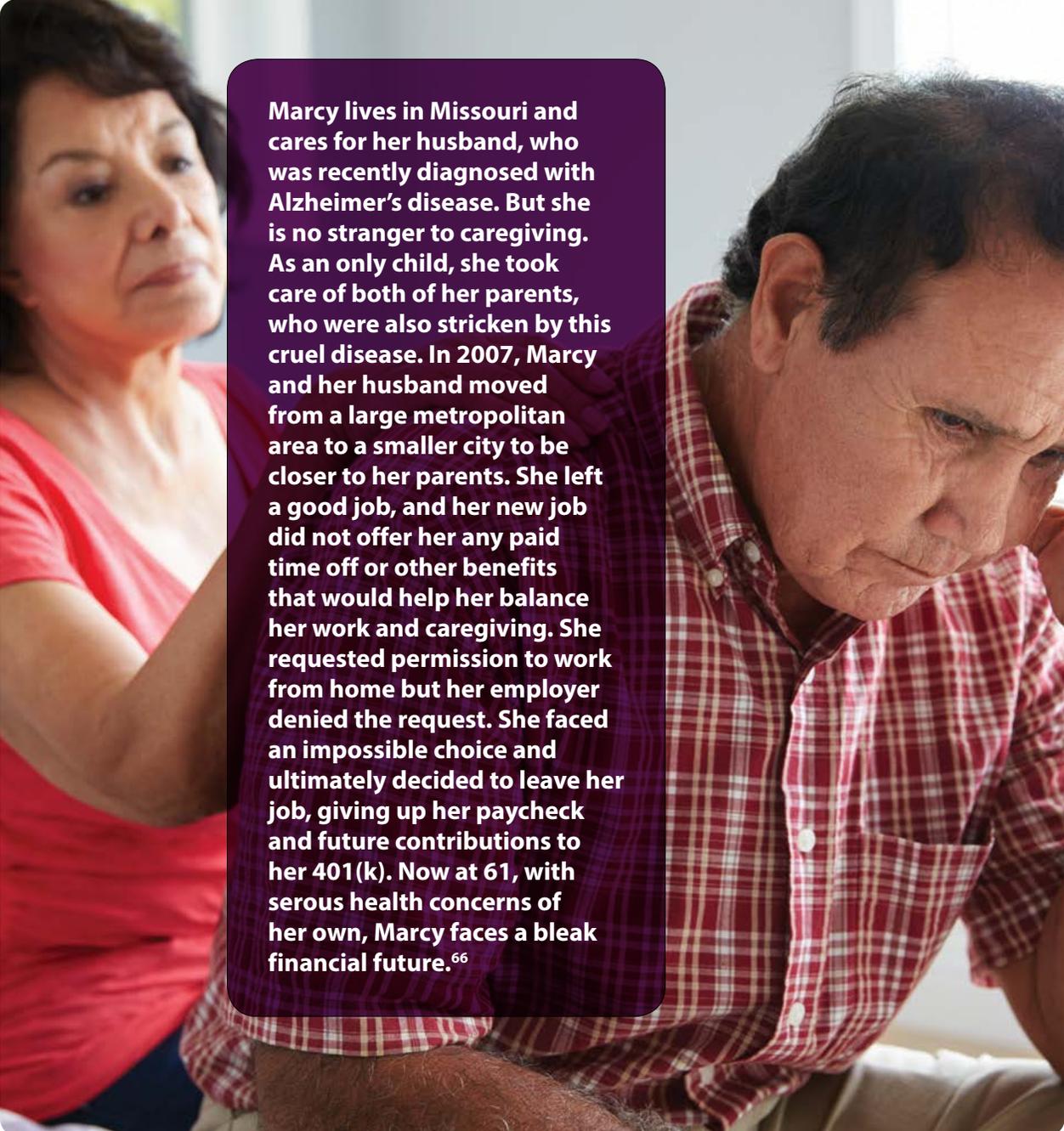
These expenses, often unanticipated, lead some caregivers to draw from their savings or reduce their own quality of living. For example, the 2016 AARP study of caregiving costs found that caregivers used a variety of ways to manage out-of-pocket costs (note that 85 percent of care recipients were age 50 and older). Nearly half of caregivers reported cutting back on leisure activities such as eating out or vacations (45 percent), while many had to cut back on necessities like their own doctor visits (19 percent), groceries (18 percent), or their own medicine (13 percent). Many caregivers dipped into personal savings (30 percent), reduced retirement savings contributions (16 percent), or dipped into existing retirement savings (11 percent).<sup>57</sup>

Some caregivers face more dire choices. A 2016 Alzheimer's Association survey found that individuals providing financial assistance and/or caregiving to a friend or relative with dementia also experienced food insecurity, with nearly one-third eating less and one in five going hungry because they couldn't afford to put food on the table.<sup>58</sup>

Caregivers, particularly those providing intensive care, also risk falling into poverty.<sup>59</sup> Women who provide intensive caregiving are particularly vulnerable, as women are already more likely to live in poverty and receive public assistance and are more likely to be caregivers than men.<sup>60</sup> Lower-income caregivers are also more likely to be the care recipient's sole unpaid help and less likely to have paid help.<sup>61</sup> Thus it is likely that they will face greater financial repercussions than their higher-income counterparts.

Work interruptions make it more difficult for caregivers to save for their later years and the effects of caregiving on retirement can be pronounced. Working eldercare givers are primarily middle-aged (57 percent are ages 45 to 64), at the peak of their earning potential, and a quarter are nearing retirement (ages 55 to 64).<sup>62</sup> In addition, because workers in their peak earning years have a high likelihood of needing to take care of their parents or parents-in-law, if they leave work at this stage of their careers,

their income in retirement is likely to suffer as well.<sup>63</sup> According to an Alzheimer's Association survey, one in five people who contributed to caring for a friend or relative with Alzheimer's disease or another form of dementia used their retirement savings to help pay for the care recipient's needs.<sup>64</sup> Recently, the Center for American Progress estimated that the cost of lost wages due to lack of paid leave to care for ill spouses, parents, or children is \$1.7 billion per year for workers ages 18 to 64.<sup>65</sup> However, these figures do not include the lost pension and retirement account contributions, nor other benefits that would compound the harm to workers' financial security over the short and long term.



**Marcy lives in Missouri and cares for her husband, who was recently diagnosed with Alzheimer's disease. But she is no stranger to caregiving. As an only child, she took care of both of her parents, who were also stricken by this cruel disease. In 2007, Marcy and her husband moved from a large metropolitan area to a smaller city to be closer to her parents. She left a good job, and her new job did not offer her any paid time off or other benefits that would help her balance her work and caregiving. She requested permission to work from home but her employer denied the request. She faced an impossible choice and ultimately decided to leave her job, giving up her paycheck and future contributions to her 401(k). Now at 61, with serious health concerns of her own, Marcy faces a bleak financial future.<sup>66</sup>**

## Work-Family Conflict Can Hurt Employers and the Economy, Too

When work and family responsibilities collide, in addition to workers potentially losing wages, hours, and savings, employers also may pay a price in lost productivity and the expenses associated with recruiting new workers.<sup>67</sup>

If workers stay in the workforce to attempt to balance work and caregiving, employers need policies to help them manage. Without such systems in place, productivity could decline as distracted and stressed workers attempt too much. But policies can help maintain productivity. Giving workers the peace of mind that their job will be there when they return will allow workers to take the time they need and return focused and ready to work. In the meantime, employers with work-life policies such as paid leave can also institute policies to ensure that work tasks can be accomplished on a different schedule or by team members. Furthermore, without work-family policies, employers could lose out on valuable, trained talent, including workers' experience and institutional knowledge. Furthermore, employers would need to spend money to recruit, hire, and train new staff, which is a costly process.

The negative consequences for the economy as a whole mirror the costs for individual employers. When working caregivers are forced to reduce their hours or drop out of the labor force and give up income by doing so, and when employers experience declining productivity or lose valuable employees and have to spend money replacing them, aggregate economic output can be dragged downward. And due to the career repercussions for individual employees discussed above, the impacts could extend for years.

By implementing policies that reduce or prevent workers from reducing hours or leaving the workforce, work-life policies can also prevent the negative effects on employers and the economy. In 2011, a MetLife study recognized that as life expectancy increases, more workers will have eldercare responsibilities. It urged employers to put in place workplace accommodations such as flexible work arrangements, "so that caregivers can continue to stay in the work force while caring for a relative."<sup>68</sup> The benefits of work-life policies are clear, as this report will now discuss.

# Finding Balance: Work-Life Policies to Help Working Eldercare Providers

As our loved ones age, they will rely on a shadow workforce of tens of millions of family members, friends, and neighbors who provide the supports and assistance they need to age with dignity and grace. There are a variety of workplace policies that can alleviate work-family conflict by giving caregivers what they need most: the time to fulfill their eldercare obligations, including having paid time off to take their loved ones to medical appointments, enough flexibility and predictability in their schedules to respond to the unpredictable nature of caring for an elder, and longer-term leave when the provision of care requires a working caregiver's full attention. Caregivers themselves report the need for these policies.<sup>69</sup> While different caregivers will have different needs that may vary over time, these public and workplace policies all have a critical role to play in easing work-family conflict.

## The Benefits of Work-Family Policies

Alleviating the work-family conflict that results from caregiving will benefit workers, employers, and the economy as a whole. Numerous studies have found that work-life policies also promote financial stability and increase workforce participation, as well as improve physical and mental health and employee morale.<sup>70</sup>

Women caregivers in particular benefit from these policies.<sup>71</sup> Women are more likely than men to provide more hours of care and more physical and direct care to their elderly loved ones, which can make balancing caregiving with a job more difficult.<sup>72</sup> Research shows that working women with caregiving responsibilities and with workplace policies that provide flexibility are more likely to stay employed, and those with access to benefits including health insurance, family leave, and paid sick days or vacation days are able to maintain or increase the hours they work.<sup>73</sup>

Work-life policies also are more likely to contribute to positive mental and physical health outcomes. In 2011, researchers studied how “paid leave and flexibility policies mediate the relationship between caregiving and health.” They studied caregivers of children and adults and found that paid leave and sick days buffered the strains of caregiving and improved both self-rated mental health and self-rated physical health. This was true even when controlling for a number of other workplace and demographic characteristics that could impact both.<sup>74</sup>

Work-life policies are a win-win for employers as well. At the start, they can be an important recruitment tool, especially as workers are increasingly looking for balance in their work and family lives. Work-life policies also increase the job satisfaction, loyalty, and commitment of employees.<sup>75</sup> The policies help keep experienced staff in place; they increase retention, inducing workers to stay in the workforce. This in turn avoids productivity losses and turnover costs from replacing experienced staff.<sup>76</sup> A coalition of business leaders, ReACT (Respect a Caregiver's Time), studied employer practices and found that scheduling flexibility and paid leave for caregivers are best practices employers can adopt to improve productivity, reduce absenteeism, retain employees, improve recruitment, reduce stress in the workplace and enhance employee loyalty.<sup>77</sup> They also found that when employers invest a dollar in flextime, they can anticipate a return of between \$1.70 and \$4.34.<sup>78</sup> Corporate Voices for

Working Families describes the “imperative” of flexibility policies, which drive financial performance and correlate to increased revenue generation and positive impacts on client services.<sup>79</sup>

## Paid Family Leave

Paid family leave is critical for caregivers of elders. It allows several weeks of time off when serious health needs arise – whether it be to assist a mother during a hospital stay or to care for a sister at home with cancer. (Short term leave, called paid sick time, is covered in the following section.) Paid family leave can lower worker stress, lighten financial worries, and improve worker morale.<sup>80</sup> Other studies’ modeling of the impacts of paid leave policies show how these policies can encourage more work, and full-time work in particular, among women who provide time-consuming and demanding care.<sup>81</sup> Furthermore, paid family leave is incredibly popular with the public: According to a recent poll of Americans age 40 and older, nearly three-quarters of those surveyed support state paid family leave programs.<sup>82</sup> However, only 14 percent of U.S. workers have access to paid family leave through their employers, although that has increased from 11 percent in 2010.<sup>83</sup>

24

Paid family leave fills in a gap in current policies. The federal Family and Medical Leave Act (FMLA), was the first national work-family policy, signed into law in 1993. It provides eligible workers up to 12 weeks of unpaid, job-protected leave to care for a qualifying family member (parents, spouse, son or daughter) with a serious health condition; address one’s own serious health condition; or for activities related to the birth or placement for adoption or foster care of a child and bonding with the child.<sup>84</sup> Critically, FMLA leave is job-protected, meaning that workers are entitled to return to their original jobs or jobs with equivalent pay, benefits, and other terms and conditions of employment, and employer retaliation against workers for taking FMLA leave is prohibited. In addition to providing eligible employees an entitlement to leave, the FMLA requires that employers maintain employees’ health benefits during leave.

The FMLA has been life-changing for millions of families, and most employers report that it is easy to comply with.<sup>85</sup> However, the FMLA has limitations. First, its reach is limited: About forty percent of workers do not meet all of the eligibility requirements for FMLA leave.<sup>86</sup> Second, it is unpaid. In 2012, nearly one-half (46 percent) of surveyed, eligible and covered workers who needed FMLA-type leave over the previous 12 months but did not take it stated that they did not take the leave because they could not afford to take unpaid time off.<sup>87</sup> For others, despite the law’s protections, their request was denied (6 percent) or they feared they might lose their job (17 percent).<sup>88</sup> Furthermore, of the covered and eligible workers who took leave and were either unpaid or only partially paid during this leave, nearly 60 percent found it difficult to make ends meet during their time off.<sup>89</sup> About one-third of these leave-takers spent savings they had earmarked for other purposes, put off paying bills, or cut their leaves short; 28 percent borrowed money; and nearly 10 percent went on public assistance.<sup>90</sup>

In this context, important complements to the FMLA are state-based paid family leave programs, also called “temporary caregiver insurance” or “family leave insurance.” California, New Jersey, and Rhode Island have already established such programs. New York passed a law in 2016 that will go into effect in 2018. These programs are all social insurance with the same basic features: Employees make a small contribution from their paychecks, which funds leave for most workers when they need it. Current programs provide partial wage replacement (ranging from 55 percent to two-thirds of wages, up to a cap) for 4 to 6 weeks of leave. (New York’s program will provide up to 12 weeks of leave and replace 67 percent of wages, capped at two-thirds of the statewide average weekly wage, when it is fully in effect.)

State paid family leave programs are critical supports, but implementation challenges remain, particularly for eldercare providers. Relatively few working caregivers for the elderly are taking advantage of them, as claims for parental leave to bond with a new child overwhelmingly outnumber caregiving claims, according to recent research commissioned by the U.S. Department of Labor.<sup>91</sup> Lack of awareness, fear of employer reprisals, restrictions on who can receive care (i.e. the definition of family), the need for differing increments of leave, low wage replacement rates, and the lack of job protection all prevent or deter workers from taking advantage of the laws.<sup>92</sup>

Eldercare providers have several unique challenges in making effective use of paid leave programs. They often need leave in different increments of time, as opposed to one uninterrupted block of time. The need for small amounts of leave on a long-term basis was singled out as an important feature of paid family leave programs by caregivers in recent focus group research.<sup>93</sup>

Another issue for eldercare providers that will no doubt need more attention in the future is the need to create an inclusive definition of the family and other relationships that qualify for taking paid leave. This issue is key for people providing care for elders and will become even more so as growing numbers of elders rely on friends and family members other than their own children for care. As shown in the Relationships chart above, 53 percent of eldercare providers are caring for someone other than a spouse or parent. California has gone the furthest in this respect. As of 2014, the California law allows care for parents-in-law, grandparents, grandchildren, and siblings.

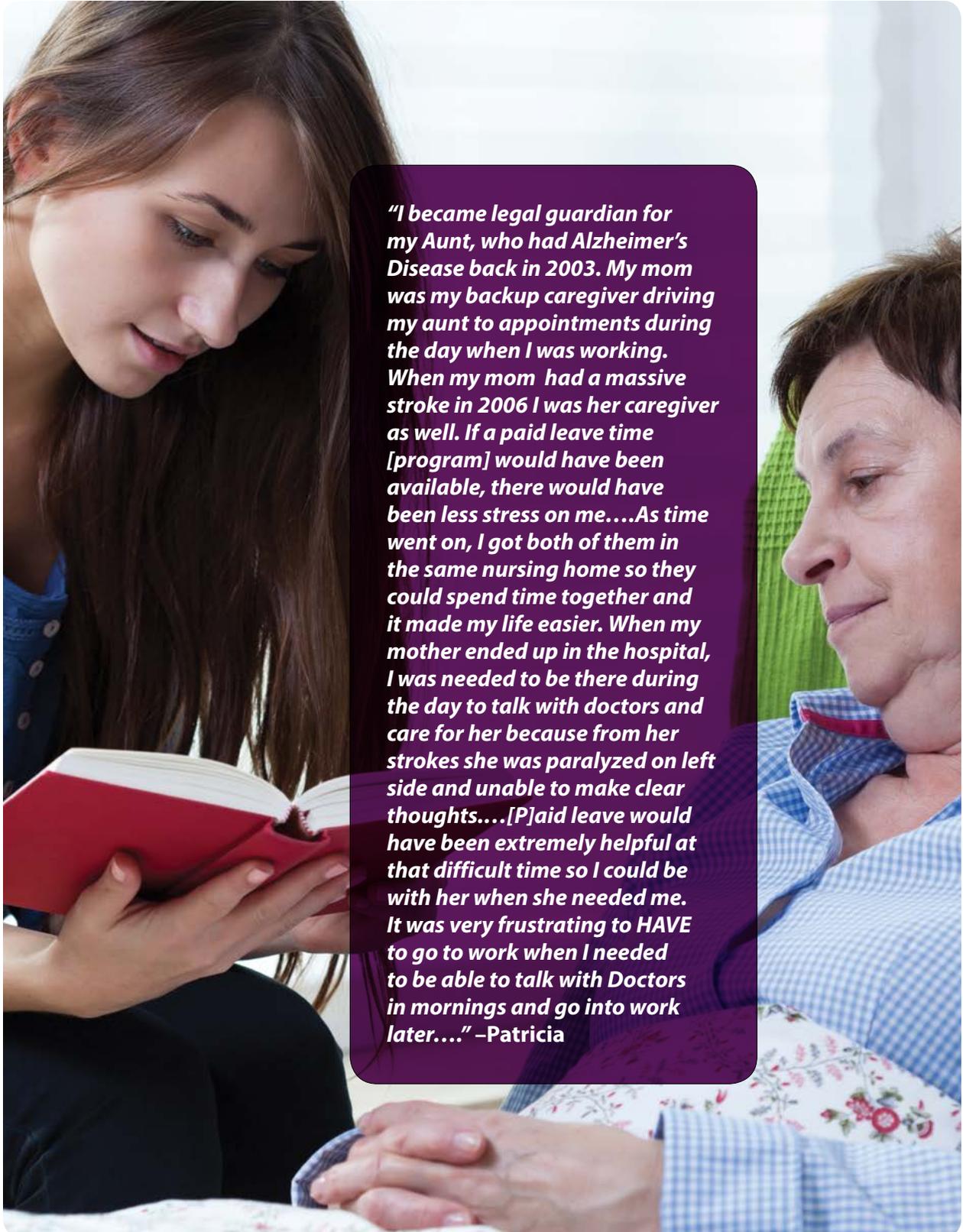
The Obama Administration is strongly supportive of efforts to implement and expand paid family and medical leave, including a call for national paid leave legislation by President Obama.<sup>94</sup> Senior Administration officials, including Secretary of Labor Thomas E. Perez, have traveled across the country to talk to business leaders, policymakers, workers, worker advocates, and other stakeholders about the critical need for paid leave. Additionally, since 2014, the department's Women's Bureau has provided grants on a yearly basis to support research and analysis on paid family and medical leave programs at the state and municipal levels; the 2016 grant program has a particular focus on leave needs related to elder caregiving.<sup>95</sup>

## Recommendations

- Congress should pass a national law that provides universal access to paid family leave.
- In the interim, states should establish their own paid family leave programs.
- To ensure they meet the needs of caregivers of the elderly, state- and local-level programs should allow care for a variety of family members and other loved ones, defined broadly to encompass those who lack marital or blood relationship.

## Additional policy options for future paid family leave programs

- Allow for short-term or intermittent leave, on an hourly or daily basis.
- Include job protection.
- Conduct aggressive outreach to stakeholders as well as ongoing public awareness campaigns and target hard-to-reach communities.



*"I became legal guardian for my Aunt, who had Alzheimer's Disease back in 2003. My mom was my backup caregiver driving my aunt to appointments during the day when I was working. When my mom had a massive stroke in 2006 I was her caregiver as well. If a paid leave time [program] would have been available, there would have been less stress on me....As time went on, I got both of them in the same nursing home so they could spend time together and it made my life easier. When my mother ended up in the hospital, I was needed to be there during the day to talk with doctors and care for her because from her strokes she was paralyzed on left side and unable to make clear thoughts....[P]aid leave would have been extremely helpful at that difficult time so I could be with her when she needed me. It was very frustrating to HAVE to go to work when I needed to be able to talk with Doctors in mornings and go into work later...." –Patricia*

## Paid Sick Time

Eldercare providers also need to be able to take time off for a broad range of reasons, and on short timeframes, which is where paid sick time fits in. Paid sick time is a cost-effective, modest policy that employers and workers alike agree is critical to the health and well-being of working families. In a recent survey, over one-third of working caregivers (for people of all ages) cited paid sick days for family members as the work-life benefit they could use the most.<sup>96</sup>

Paid sick time laws in the United States have features that are especially important for caregivers of the elderly. The laws usually allow workers to earn, on the basis of hours worked, 24 to 72 hours of leave per year.<sup>97</sup> Because this leave is paid and job protected, workers do not need to risk their paychecks or positions to provide care. It complements paid family leave. Workers can generally use paid sick time in small, even hourly, increments, allowing them to use up their leave more slowly. Paid sick time can be more flexible than paid family leave in that it allows time off for short-term illness and preventive care, and ranging from intensive to everyday caregiving tasks.

A major benefit of paid sick days is that workers can often provide care for a wider array of loved ones than paid family leave, often for a long list of familial relationships and sometimes even beyond. For example, in Chicago and Los Angeles, which both recently passed new or expanded upon existing laws, workers will be able to provide care for any loved one with whom the worker has the equivalent of a family relationship, even if there is no blood relationship. Workers on federal contracts, who will begin in 2017 to earn the right to paid sick time under an Executive Order issued by the President, will also be able to take leave for loved ones with whom the worker has the equivalent of a family relationship.

Paid sick time laws also usually allow workers to take unforeseen leave without notice and without needing to find a replacement worker. This flexibility can be critical for caregivers of the elderly who often can't predict when there will be a crisis or other need.

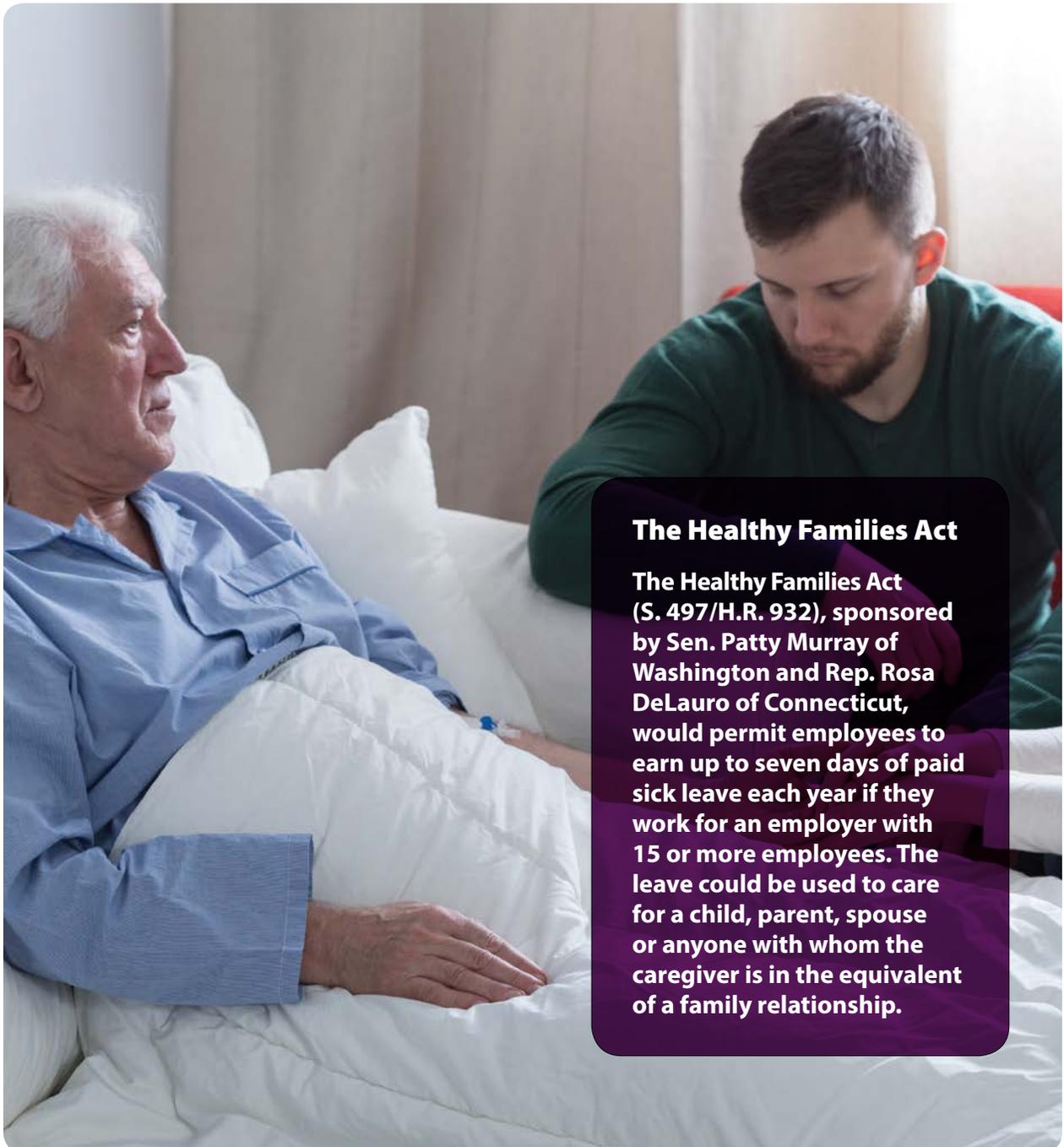
This time off is beneficial for recipients as well as caregivers' own care. A caregiver who runs herself down physically or psychologically from the stress of caring for an elder could use paid sick time to see a doctor for her own health needs.

Paid sick days for caregivers also benefit employers and the economy. Paid sick days boost recruitment and retention and lift morale and job satisfaction. Businesses can realize cost savings as policies reduce costly turnover and the replacement costs from recruiting, hiring, and training new workers.<sup>98</sup>

Unfortunately, tens of millions of America's workers do not have any paid sick time. Indeed, one in three private-sector workers do not have access to even one paid sick day, and lower-wage workers as well as Hispanic or Native American workers are less likely to have access.<sup>99</sup> In addition, employer-based paid sick time policies are often limited to care for oneself and exclude caregiving of others. For example, only 53 percent of working caregivers for people age 50 and over report access to paid sick days, according to the NAC/AARP survey.<sup>100</sup> An employer survey in 2014 showed that only 34 percent of employers offered at least five days off per year for caring for an elderly relative without losing pay or having to use vacation days.<sup>101</sup>

There has been significant progress at the state and municipal levels. Five states – Connecticut, California, Massachusetts, Oregon, and Vermont – as well as Washington D.C. and more than two dozen local governments have passed paid sick time legislation.<sup>102</sup> With the exception of the

Connecticut law, all of these laws allow covered workers to use paid sick time to care for parents and/or grandparents.<sup>103</sup> The momentum is likely to grow both in legislation and as more voters consider ballot measures to establish paid sick time in their states or cities. In addition, in September 2015 President Obama signed the aforementioned executive order to allow workers on certain “new” federal contracts to earn up to seven paid sick days per year that they can use to care for a loved one or for self-care. The policy will go into effect in 2017.



### **The Healthy Families Act**

**The Healthy Families Act (S. 497/H.R. 932), sponsored by Sen. Patty Murray of Washington and Rep. Rosa DeLauro of Connecticut, would permit employees to earn up to seven days of paid sick leave each year if they work for an employer with 15 or more employees. The leave could be used to care for a child, parent, spouse or anyone with whom the caregiver is in the equivalent of a family relationship.**

## Recommendations

- Congress should pass the Healthy Families Act to ensure that paid sick time is available regardless of where one lives and to establish a national standard.
- Additional states and cities should pass laws to establish paid sick time policies. These laws should:
  - Provide at least seven days of leave.
  - Allow workers to use leave in small increments.
  - Not require workers to find replacements when they need to use paid sick time.
  - Allow workers to use leave for a wide variety of relationships, including loved ones not related by blood.

## Right to Request Workplace Flexibility and Scheduling Predictability

Work interruptions are in many ways a defining feature of much eldercare.<sup>104</sup> But they can be managed with the right policies. The unpredictability, irregularity, and length of eldercare call for scheduling flexibility – and in many cases, predictability – that would go far to help caregivers of the elderly balance their responsibilities and ensure they can continue working. Flexibility comes in many forms, but the central feature is control over where and when one works. For example, it could include teleworking – which could be from a worker’s home, from a care recipient’s home, or even from the hospital in the event of an emergency – as well as the ability to start or stop work at different times.

Expanding flexibility policies not only benefits employees, increasing their job satisfaction and reducing the stress that comes with work-life conflict, but can be beneficial for employers as well. Workplace flexibility increases employee retention and commitment; reduces the costs associated with turnover, recruitment and absenteeism; improves client services and customer relations; and boosts productivity.<sup>105</sup> According to an in-depth analysis of work flexibility policies conducted by Corporate Voices for Working Families, many businesses consider their flexibility policies beneficial to their bottom lines. For example, as a result of its workplace flexibility policies, Deloitte & Touche LLP found that it had saved over \$40 million dollars in turnover-related costs in 2003. And First Tennessee Bank reported that its policies increased employee satisfaction, which in turn improved customer retention, leading to an over \$100 million profit increment during a two-year time period.<sup>106</sup>

The need for caregivers to have a predictable schedule is critical, particularly for hourly workers in the context of the growing use of just-in-time scheduling in industries like retail and other services, in which employers may call workers in at a moment’s notice. This can wreak havoc with eldercare schedules, doctor’s appointments, and other needs.<sup>107</sup> There is anecdotal evidence that guaranteed schedules help with retention, as Costco has experienced.<sup>108</sup> However, more research is needed to demonstrate the impacts of these policies, particularly as they affect workers with caregiving responsibilities.

Unfortunately, workplace flexibility is not the norm for many working Americans. In 2011, only 56 percent of wage and salary workers responding to the American Time Use Survey reported that they could adjust their schedule or location, with 53 percent being able to adjust schedules and 22 percent being able to change location.<sup>109</sup> Workers who were more educated and had higher incomes were considerably more likely than less-educated and lower-income workers to be able to adjust their schedule or location. These disparities apply across the board to all kinds of work flexibility, including

scheduling hours, days worked, and the location of work.<sup>110</sup> For example, a national study of employers showed that just over 80 percent of firms with over 50 employees in 2014 allowed some workers to change starting and quitting times periodically, but only 27 percent allowed this for most or all of their employees.<sup>111</sup>

There has been some headway made in public policies: in recent years Vermont (2013), New Hampshire (2016), and San Francisco (2013) passed laws to give workers the “right to request” work arrangements that work for them; employers are required to consider those requests without retaliating against workers for making them. This type of legislation allows workers and employers to determine the best solution for the situation at hand without mandating a particular solution that may not fit all circumstances. It also ensures that workers can safely make requests without risking their paychecks.

The Obama Administration has instituted a flexibility policy for federal workers, including those caring for elderly loved ones.<sup>112</sup> This includes the right to request work schedule flexibilities, including telework, part-time work or job sharing and the obligation of supervisors to consider the request and respond back no later than 20 business days after the request is made.

### Policy options to consider for fair and predictable scheduling

- Legislation at the national, state, and municipal level that provides workers with the “right to request” schedules that work for them would particularly help eldercare providers balance their frequent and varied demands of caregiving.
- Legislation that ensures workers are protected from retaliation if they make such a request would encourage eldercare providers to access such flexibility options.
- Legislation that requires employers to respond to such requests and an affirmative obligation to try to find a mutually agreeable solution would help eldercare providers balance their work and care demands.



Barbara, who is in her seventies and lives in California, cared for her elderly mother with dementia for over eight years. She owns her own business and can set her own schedule. While her mother resided in assisted living facilities, Barbara was very involved in all aspects of her care, and these activities were very time-consuming. At the same time, she was determined to keep her business afloat and, as long as she had her laptop computer, she was able to work remotely whenever she had time. While balancing work and supporting her mother was very difficult, she was able to manage both because she had the kind of flexibility to work from her office, a waiting room, or her mother's bedside.<sup>113</sup>



Mary Helen can manage her work and caregiving duties for her elderly mother because she has workplace flexibility. She is in her fifties and lives in Maryland. She lives in the same apartment complex as her mother, who is in her nineties and has mobility issues and failing eyesight due to macular degeneration. While Mary Helen's mother currently lives independently, she still needs a lot of help. Mary Helen is a tenured college professor. As such, she has flexibility and predictability in her schedule to balance both work and care. She can set her own office hours for students, and while she has a teaching schedule, she can still provide care. Mary Helen needs this flexibility and predictability to help her mother, but she does worry about what will happen if her mother needs more intensive long-term care in the future.<sup>114</sup>

## Business Voices

A photograph showing three business professionals in a meeting. A man in a dark suit is seated on the left, looking towards a woman in a black blazer on the right. Another woman in a light blue top is seated in the foreground, looking down at a document. They are all gathered around a light-colored wooden table with papers and blue pens.

***“I actually see better productivity from employees who use flextime or activities like that because they are dedicated to the company, they know they may have that responsibility and they’re thankful for what the company did to be able to give them the flexibility of deciding when and how to do their work. The empowerment aspect of these programs is just fantastic.”***

–Dick Clark, Merck former Chairman and CEO, 2010<sup>115</sup>

***“Family-friendly work schedules and benefits are about having lower stress levels, maintaining better health, and enabling a stronger focus when at work –all leading to enhanced engagement, increased innovation and ultimately better results.”***

–Steve Fry, Eli Lilly senior vice president of human resources and diversity, 2012<sup>116</sup>

## Combating Caregiver Discrimination

A major challenge that working caregivers face is negative reactions from employers—or fear of possible negative reactions.<sup>117</sup> Research with focus groups commissioned by the U.S. Department of Labor showed that this was one of the biggest concerns caregivers raised.<sup>118</sup> The NAC/AARP survey shows that among working caregivers for those age 50 and older, just over half report that their supervisor knows about their caregiving responsibility.<sup>119</sup> Workers are often afraid to tell their employers about their caregiving responsibilities, lest they be penalized, stereotyped, or discriminated against. The NAC/AARP survey shows that among all working caregivers, two-thirds support banning workplace discrimination against workers with caregiving responsibilities.<sup>120</sup>

Discrimination based on caregiving (for children, the elderly or disabled adults), or Family Responsibilities Discrimination (FRD), occurs when an “employee suffers an adverse employment action based on unexamined biases about how workers with family caregiving responsibilities will or should act without regard to the worker’s actual performance or preference.”<sup>121</sup> Family Responsibilities Discrimination comes in many forms: It can include outright firing of caregivers or stereotyping them as less committed or competent because they have taken leave. Discrimination also occurs when an employer treats caregiver employees differently than other employees, or takes other actions, such as implementing scheduling changes designed to penalize caregivers.<sup>122</sup>

Employers pay a price when they discriminate against their employees. Discriminatory practices can result in legal claims, with related litigation expenses and legal damages.<sup>123</sup> Employers may also suffer losses in personnel, productivity, employee morale, and reputation.<sup>124</sup>

As more workers provide care to elders due to the aging of the population and the growing demand for care, instances of discrimination based on eldercare giving are growing.<sup>125</sup> A 2016 report from the Center for WorkLife Law at the University of California, Hastings College of the Law, calls eldercare the “new frontier.” It noted that, among the 4,400 FRD cases it has reviewed, cases related to caregiving for aging relatives filed by employees against their employers have increased by more than 650 percent in the last decade.<sup>126</sup> Men now account for nearly 40 percent of these eldercare cases.<sup>127</sup>

Although federal equal employment opportunity laws do not prohibit discrimination against caregivers per se, there are circumstances in which discrimination against caregivers might constitute unlawful disparate treatment under Title VII of the Civil Rights Act of 1964, as amended, or the Americans with Disabilities Act (ADA).<sup>128</sup> In 2007, the U.S. Equal Employment Opportunity Commission (EEOC), which enforces Title VII and the ADA, issued enforcement guidance regarding unlawful disparate treatment under the federal equal employment opportunity laws of workers with caregiving responsibilities.<sup>129</sup>

Under Executive Order 11246, which is enforced by the U.S. Department of Labor’s Office of Federal Contract Compliance Programs, federal contractors may not treat female or male employees or applicants differently based on the stereotypical assumption that women are more likely to have caregiving responsibilities. It would constitute sex discrimination for an employer not to hire a female applicant because the employer assumes that caregiving obligations will interfere with her ability to do her job.<sup>130</sup> And contractors may not deny men flexible workplace arrangements that are available to women based on the faulty assumption that men do not have and do not assume caregiving responsibilities.<sup>131</sup>

In Canada, the national human rights law protects people from discrimination in employment or receipt of federal services based on their family status. Courts have further determined that this law applies with regard to family caregiver responsibilities.<sup>132</sup> In addition, there are some public policies in the U.S. that expressly include family responsibilities or familial status as a protected category in their laws prohibiting employment discrimination. There are protections in Minnesota (familial status or status as a family caregiver), New Jersey (familial status), Alaska (parenthood), and Washington, D.C. (family responsibilities), as well as in a number of municipalities.<sup>133</sup> Thus caregiver discrimination protections are an area ripe for attention.

#### Policy options on caregiver discrimination

- Legislation at the federal, state, and municipal levels that prohibits discrimination based on family responsibilities or caregiver status would provide unpaid eldercare providers who work outside the home more security and confidence that they would not lose their jobs because of their caregiving responsibilities.
- Because elder caregiving needs are varied, legislation that includes a broad definition of caregiving and who may provide care best suits the needs of eldercare providers.
- Many existing regulations and statutes that prohibit discrimination on the basis of sex stereotyping can be interpreted to cover family responsibility discrimination.



## The Role of Employers

Public policy is an efficient, universal way to ensure that all workers have access to the supports and protections they need to be good workers and to take care of their families. But employers can play an essential role by their voluntarily adopted policies as well. By voluntarily instituting the policies described above – from paid family leave and paid sick days to flexibility and creating supportive work environments – employers can make significant contributions to work-family balance.

Furthermore, employers can also offer a suite of benefits that help their workers navigate the complicated world of long-term care and elder support. These may include backup adult care, geriatric assessments, social workers, referral services, and financial or emotional counseling.<sup>134</sup> Other activities may include brown bag lunch-and-learn seminars, caregiver fairs, and enhanced information and referral. According to a recent employer survey, 43 percent of employers with 50 or more employees give workers information about eldercare services.<sup>135</sup> Companies with the necessary resources may offer these services through Employee Assistance Programs.<sup>136</sup>

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Many employers are already taking these steps. For example, across the country, employers are instituting paid family leave and sick time policies, even when not required to do so by law. While long-term leave is much more common for new parents, companies such as Patagonia, Nike, and Deloitte LLP ensure that workers can also take time off to care for sick loved ones.<sup>137</sup>

A coalition of businesses has come together to address the challenges of working caregivers in ReACT (Respect a Caregiver's Time); together they employ nearly 1 million workers. The coalition has produced helpful resources for working caregivers and their employers. In its report on best practices in workplace eldercare, ReACT highlights companies that are providing more innovative benefits to workers with eldercare responsibilities. These include discounted back-up emergency home care, geriatric care management services, help with insurance paperwork and information about insurance policies, and more.<sup>138</sup>

## Conclusion

As a growing share of the American population moves into their golden years, working people are called upon to care for their aging loved ones. The contributions of the virtual army of unpaid eldercare providers cannot be overstated. While they sacrifice their time and often their own health and economic well-being in order to care for older Americans, their care makes a real difference in the lives of their elderly loved ones, the economy, and society as a whole.<sup>139</sup> Whether by providing hands-on care at home, managing finances, doing household tasks, or acting as an ill patients' advocate in the hospital, our parents, grandparents, siblings, friends, neighbors, and other loved ones will count on our help and care.

It is a challenge for working eldercare providers to balance the needs of caregiving with the demands of a job. Too many workers are stressed to the breaking point and some are forced to reduce their work hours or potentially drop out of the workforce. This is bad for their own financial situation as well as for businesses and the economy as a whole.

However, work-family policies – such as paid family leave, paid sick days, scheduling flexibility and predictability, and preventing discrimination against caregivers – are a small investment compared to the benefits they provide for working caregivers, the older Americans for whom they care, their employees, the economy, and society as a whole.



These policies are not only associated with better physical, mental, and financial health outcomes for caregivers, they may help caregivers remain in the workforce and older Americans needing care remain at home. They are good for business because they can improve productivity and retention and reduce absenteeism.

In addition, allowing working eldercare providers the ability to balance their work and caregiving responsibilities will alleviate, at least in part, the growing concern about whether the aging of the baby boomers and growing demand for long-term care can be met by informal care. Workforce supports also promote gender equality by removing one of the barriers to women's full participation in the workforce and, if applied across-the-board, would help level the playing field for all caregivers regardless of income, race or education, providing benefits to those workers who need them the most.<sup>140</sup>

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Some private employers recognize the value of these benefits and provide them, especially to higher-income workers, but a large proportion of American workers in the private sector have no access to paid family leave, sick days, or work flexibility when they need time to care for an older family member.<sup>141</sup>

The Obama Administration has been committed to promoting work-life balance and has sought to extend many of these policies to federal workers so they can work and also take care of their elderly loved ones. Paid family leave, sick days, and workplace flexibility should be extended to all workers. They are consistent with our most fundamental values, including the importance of an honest day's work for an honest day's pay, honoring our mothers and fathers, caring for those who are ill and in need of care, and promoting equality of opportunity for all Americans.

Supporting caregivers to keep their jobs and make their caregiving responsibilities easier is an essential way to value our elders and repay informal, unpaid caregivers for the valuable contributions they make to their loved ones, the economy, and society as a whole.

# Endnotes

<sup>1</sup> Unless otherwise noted, this and other individual stories were submitted to the Department of Labor via a story-collection tool on [www.dol.gov/paidleave](http://www.dol.gov/paidleave).

<sup>2</sup> Bureau of Labor Statistics, "Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey," Table 1 (Number and Percent of the U.S. Population who were Eldercare Providers by Sex and Selected Statistics, Averages for the Combined Years 2013-2014), September 23, 2015, retrieved from <http://www.bls.gov/news.release/pdf/elcare.pdf>; unpublished tabulations of working caregiver characteristics derived from American Time Use Survey 2013-2014; data provided to the Department by the Bureau of Labor Statistics.

This report uses data from the Bureau of Labor Statistics (BLS) American Time Use Survey report when available, including unpublished information on working caregivers; BLS defines eldercare providers broadly, as BLS notes: "Eldercare providers are defined as individuals who provide unpaid care to someone age 65 or older who needs help because of a condition related to aging. This care can be provided to household or non-household members, as well as persons living in retirement homes or assisted care facilities. Eldercare can involve a range of care activities, such as assisting with grooming, preparing meals, and providing transportation. Eldercare also can involve providing companionship or being available to assist when help is needed, and thus it can be associated with nearly any activity."

When BLS data is not available, information from other surveys is used. First, the U.S. Department of Health and Human Services' (HHS) Assistant Secretary for Planning and Evaluation (ASPE) estimated that there were 18 million caregivers of the elderly in 2011, about half of whom worked for pay. HHS reported on the National Survey of Caregiving (NSOC), which interviewed informal caregivers of people age 65 or older receiving assistance with daily activities. This population was determined by contacting survey respondents to the National Health and Aging Trends Survey who reported that they received care from informal caregivers in the previous month; the surveyors then contacted those caregivers for the NSOC. See Brenda Spillman, et al., "Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving," April 2014, p. 12, retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/77146/NHATS-IC.pdf>.

Second the National Alliance of Caregiving and AARP Public Policy Institute conducted a survey of 1,087 unpaid family caregivers and estimated that 34.2 million adults served as unpaid caregivers to someone aged 50 or older in 2014 (see National Alliance for Caregiving and AARP Public Policy Institute, "Caregivers of Older Adults: A Focused Look at Those Caring for Someone Age 50," June 2015, retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/caregivers-of-older-adults-focused-look.pdf>) (referred to throughout as the NAC/AARP and NAC/AARP survey).

<sup>3</sup> Ann Bookman and Mona Harrington, "Family Caregivers: A Shadow Workforce in the Geriatric Health Care System," *Journal of Health Politics, Policy and Law*, vol. 32, no. 6, December 2007, p. 1010, retrieved from <http://gjic.rgps.on.ca/files/family%20caregivers%20the%20shadow%20workforce.pdf>.

<sup>4</sup> U.S. Census Bureau, "Millennials Outnumber Baby Boomers and Are Far More Diverse," Release Number CB15-113, June 2015, retrieved from <http://www.census.gov/newsroom/press-releases/2015/cb15-113.html>.

<sup>5</sup> Heather Boushey, *Finding Time: The Economics of Work-Life Conflict*, (Cambridge, MA: Harvard University Press, 2016).

<sup>6</sup> Barbara Butrica and Nadia Karamcheva, "The Impact of Informal Caregiving on Older Adults' Labor Supply and Economic Resources," The Urban Institute, October 2014, p. 19-22, retrieved from <https://www.dol.gov/ebsa/pdf/impactofinformalcaregivingonolderadults.pdf>; also see Note 46.

<sup>7</sup> Heather Boushey, *Finding Time*, p. 250-251; Lisa Calvano, "Tug of War: Caring for our Elders While Remaining Productive at Work," *The Academy of Management Perspectives*, vol. 27 no. 3, August 1, 2013, p. 212, retrieved from <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.681.3063&rep=rep1&type=pdf>; Bookman and Harrington, "Family Caregivers: A Shadow Workforce in the Geriatric Health Care System," p. 1036; Eliza K. Pavalko and Kathryn Henderson, "Combining Care Work and Paid Work: Do Workforce Policies Make a Difference?" *Research on Aging*, vol. 28 no. 3, May 2006, p. 370, retrieved from <http://www.agework.com/careersinaging/policies.pdf>.

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- <sup>10</sup> U.S. Census Bureau, "2014 National Population Projections: Summary Tables," 2014, Table 3. Projections of the Population by Sex and Selected Age Groups for the United States: 2015 to 2060, retrieved from <http://www.census.gov/population/projections/data/national/2014/summarytables.html>.
- <sup>11</sup> Ibid.
- <sup>12</sup> U.S. Department of Health and Human Services, "Long-Term Services and Supports for Older Americans: Risks and Financing," February 2016, p. 1, retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/106211/ElderLTCrb-rev.pdf>.
- <sup>13</sup> Congressional Budget Office, "Rising Demand for Long-Term Services and Supports for Elderly People," June 2013, p. 1, retrieved from: <https://www.cbo.gov/sites/default/files/113th-congress-2013-2014/reports/44363-LTC.pdf>; Joint Center for Housing Studies of Harvard University, "Housing America's Older Adults," 2015, p. 32, retrieved from [http://www.jchs.harvard.edu/sites/jchs.harvard.edu/files/jchs-housing\\_america\\_older\\_adults\\_2014.pdf](http://www.jchs.harvard.edu/sites/jchs.harvard.edu/files/jchs-housing_america_older_adults_2014.pdf); and Pamela Doty, "The Evolving Balance of Formal and Informal, Institutional and Non-Institutional Long-Term Care for Older Americans: A Thirty-Year Perspective," *Public Policy and Aging Report*, vol. 20, No. 1, Winter 2010, p. 6.
- <sup>14</sup> Congressional Budget Office, "Rising Demand for Long-Term Services and Supports for Elderly People," p. 1-2; Joint Center for Housing Studies of Harvard University, "Housing America's Older Adults," p. 32.
- <sup>15</sup> Butrica and Karamcheva, "The Impact of Informal Caregiving on Older Adults' Labor Supply and Economic Resources."
- <sup>16</sup> Carol V. O'Shaughnessey, "Family Caregivers: The Primary Providers of Assistance to People with Functional Limitations and Chronic Impairments," National Health Policy Forum, January 11, 2013, p. 4, retrieved from [http://www.nhpf.org/library/background-papers/BP84\\_FamilyCaregiving\\_01-11-13.pdf](http://www.nhpf.org/library/background-papers/BP84_FamilyCaregiving_01-11-13.pdf); Commission on Long Term Care, *Report to the Congress*, September 30, 2013, p. 13, retrieved from <https://www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf>.
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- <sup>18</sup> Commission on Long Term Care, *Report to the Congress*, p. 7.
- <sup>19</sup> Ibid, p. 13.
- <sup>20</sup> National Alliance for Caregiving and AARP Public Policy Institute, "Caregivers of Older Adults," June 2015, p. 26, retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/caregivers-of-older-adults-focused-look.pdf>.
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- <sup>22</sup> The Obama Administration supports efforts to help individuals age in their communities. See the Department of Health and Human Services, Administration on Aging, Home and Community-Based Long Term Care, available at [http://www.aoa.acl.gov/AoA\\_Programs/HCLTC/index.aspx](http://www.aoa.acl.gov/AoA_Programs/HCLTC/index.aspx).
- <sup>23</sup> Congressional Budget Office, "Rising Demand for Long-Term Services and Supports for Elderly People," p. 9.
- <sup>24</sup> Courtney Van Houtven and Edward Norton, "Informal Care and Health Care Use of Older Adults," *Journal of Health Economics*, vol. 23, December 2004, p. 1163.
- <sup>25</sup> Lynn Friss Feinberg, "The Dual Pressures of Family Caregiving and Employment: Six in Ten Family Caregivers are in the Labor Force," AARP Public Policy Institute, May 2016, p. 1-4 retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2016-03/The-Dual-Pressures-off-Family-Caregiving-and-Employment.pdf>.
- <sup>26</sup> Peggie R. Smith, "Eldercare, Gender and Work: The Work-Family Issue of the 21st Century," *Berkeley Journal of Employment & Labor Law*, vol. 25, no. 2, September 2004, p. 368, retrieved from <http://scholarship.law.berkeley.edu/cgi/viewcontent>.

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- <sup>27</sup> Smith, "Eldercare, Gender and Work: The Work-Family Issue of the 21st Century," p. 365-369.
- <sup>28</sup> Bureau of Labor Statistics, "Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey," unpublished data. For similar estimates, see NAC/AARP, "Caregivers of Older Adults," p. 10. For discussion of how eldercare needs can be unexpected and can intensify over time, see Calvano, "Tug of War: Caring for our Elders While Remaining Productive," p. 211.
- <sup>29</sup> Bureau of Labor Statistics, "Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey," unpublished data; Spillman, et al., "Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving." The NSOC study shows that average hours of caregiving rise as hours of work falls: caregivers working 20 or fewer hours per week provide 70 hours of care on average; those working 21-39 hours provide 54 hours of care; and full-time workers (40+ hours) provide 45 hours of care per month.
- <sup>30</sup> Calvano, "Tug of War: Caring for our Elders While Remaining Productive," p. 205; See also: Brigid Schulte, "Aging Population Prompts More Employers to Offer Elder-Care Benefits to Workers," *The Washington Post*, November 16, 2014, retrieved from [https://www.washingtonpost.com/local/aging-population-prompts-more-employers-to-offer-elder-care-benefits-to-workers/2014/11/16/25f9c8e6-6847-11e4-a31c-77759fc1eacc\\_story.html](https://www.washingtonpost.com/local/aging-population-prompts-more-employers-to-offer-elder-care-benefits-to-workers/2014/11/16/25f9c8e6-6847-11e4-a31c-77759fc1eacc_story.html).
- <sup>31</sup> National Institute of Mental Health, "Adult Stress – Frequently Asked Questions," retrieved from [http://www.nimh.nih.gov/health/publications/stress/stress\\_factsheet\\_in\\_142898.pdf](http://www.nimh.nih.gov/health/publications/stress/stress_factsheet_in_142898.pdf).
- <sup>32</sup> Spillman, et al., "Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving," p. 18. According to the NAC/AARP survey, two-thirds (64 percent) of all caregivers (working and non-) providing care to people age 50 and over report that caregiving is emotionally stressful, including 38 percent who report it's highly stressful; nearly one in five (19 percent) reports facing a high level of physical strain; see NAC/AARP, "Caregivers of Older Adults: A Focused Look at Those Caring for Someone Age 50," p. 35-36.
- <sup>33</sup> Spillman, et al., "Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving," p. 21.
- <sup>34</sup> NAC/AARP, "Caregivers of Older Adults," p. 33-36.
- <sup>35</sup> Ann Bookman and Delia Kimble, "Families and Eldercare in the Twenty-First Century," *Future of Children*, vol. 21, no. 2, Fall 2011, p. 124, retrieved from [http://www.futureofchildren.org/publications/docs/21\\_02\\_06.pdf](http://www.futureofchildren.org/publications/docs/21_02_06.pdf); Kerstin Aumann, et al., "Working Family Caregivers of the Elderly: Everyday Realities and Wishes for Change," Families and Work Institute, October 2010, p. 2; Bureau of Labor Statistics, "Unpaid Eldercare in the United States, 2013-2014 Data from the American Time Use Survey," Table 5. Time spent providing eldercare and percent of eldercare providers engaging in caregiving, by sex and caregiving activity, averages for the combined years 2013-14.
- <sup>36</sup> NAC/AARP, "Caregivers of Older Adults," p. 36; Smith, "Eldercare, Gender and Work: The Work-Family Issue of the 21st Century," p. 366-368.
- <sup>37</sup> Smith, "Eldercare, Gender and Work: The Work-Family Issue of the 21st Century," p. 366-368.
- <sup>38</sup> Brenda C. Spillman and Sharon K. Long, "Does High Caregiver Stress Predict Nursing Home Entry," (prepared by the Urban Institute for the U.S. Department of Health and Human Services), 2009, p. 154, retrieved from <https://aspe.hhs.gov/sites/default/files/pdf/74886/NHentry.pdf>.
- <sup>39</sup> Smith, "Eldercare, Gender and Work: The Work-Family Issue of the 21st Century"; Calvano, "Tug of War: Caring for our Elders While Remaining Productive," p. 211; Smith, "Eldercare, Gender and Work: The Work-Family Issue of the 21st Century," p. 354, 368-369.
- <sup>40</sup> NAC/AARP, "Caregivers of Older Adults," p. 40. For additional information on the impact of caregiving on caregivers' employment see White-Means and Rubin, "Retirement Security for Family Eldercaregivers with Labor Force Employment," p. 2.
- <sup>41</sup> NAC/AARP, "Caregivers of Older Adults," p. 40.
- <sup>42</sup> Ibid.
- <sup>43</sup> Ibid. Note that high-burden caregivers are those that provide higher hours of care and/or provide help with more ADLs and/or IADLs. For details of how burden level was determined, see Appendix B of the cited report.
- <sup>44</sup> Note that there is disagreement in the literature as to whether caregiving primarily negatively impacts working caregivers by increasing their likelihood of dropping out of the labor force or by causing them to reduce their hours worked. Some studies find negative impacts on labor force participation but no discernable impact on hours worked, while other studies show negative impacts on hours worked but find no discernable increase in the likelihood of workers dropping out of the labor force when they take on caregiving responsibilities. For discussions of this literature and evidence of the described findings, see Meghan M. Skira, "Dynamic Wage and

Employment Effects of Elder Parent Care," *International Economic Review*, vol. 56, no. 1, February 2015, p. 65, retrieved from <http://people.terry.uga.edu/skira/SkiralER2014.pdf>; Josephine C. Jacobs, et al., "Baby Boomer Caregivers in the Workforce: Do they Fare Better or Worse than their Predecessors?" Canadian Center for Health Economics, January 20, 2014, p. 2, retrieved from <http://www.canadiancentrefortheconomics.ca/wp-content/uploads/2014/01/Jacobs-et-al.pdf>; Josephine C. Jacobs, "The Impact of Informal Caregiving Intensity on Women's Retirement in the United States," Canadian Center for Health Economics, April 17, 2014, p. 18, retrieved from <http://www.canadiancentrefortheconomics.ca/wp-content/uploads/2014/04/Jacobs-et-al.pdf>.

- <sup>45</sup> Note the sample was also limited just to those caregivers who reported providing help specifically with ADLs or IADLs or both. See Evercare, "Evercare Study of Family Caregivers – What They Spend, What They Sacrifice The Personal Financial Toll of Caring for a Loved One," Nov. 2007, p. 21, retrieved from [http://www.caregiving.org/data/Evercare\\_NAC\\_CaregiverCostStudyFINAL20111907.pdf](http://www.caregiving.org/data/Evercare_NAC_CaregiverCostStudyFINAL20111907.pdf).
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- <sup>47</sup> Skira, "Dynamic Wage and Employment Effects of Elder Parent Care," p. 64, 79.
- <sup>48</sup> Ibid, p. 63-64. See also Fay Gordon, "Advocacy Starts at Home: Strengthening Supports for Low-Income Older Adults and Family Caregivers," *Justice in Aging*, February 2016, retrieved from [http://www.justiceinaging.org/wp-content/uploads/2016/02/FINALAdvocacy-Starts-at-Home\\_Strengthening-Supports-for-Low-Income-Adults-and-Family-Caregivers.pdf](http://www.justiceinaging.org/wp-content/uploads/2016/02/FINALAdvocacy-Starts-at-Home_Strengthening-Supports-for-Low-Income-Adults-and-Family-Caregivers.pdf).
- <sup>49</sup> NAC/AARP, "Caregivers of Older Adults," p. 61-62. See also: Feinberg, "The Dual Pressures of Family Caregiving and Employment: Six in Ten Family Caregivers are in the Labor Force," p. 3; Bookman and Harrington, "Family Caregivers: A Shadow Workforce in the Geriatric Health Care System," p. 1036.
- <sup>50</sup> Vince Zangaro, interview with Department of Labor, June 9, 2016.
- <sup>51</sup> MetLife Mature Market Institute, "Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for their Parents," June 2011, p. 2, 14-15, retrieved from <http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf>.
- <sup>52</sup> Butrica and Karamcheva, "The Impact of Informal Caregiving on Older Adults' Labor Supply and Economic Resources," p. 19-22.
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