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ECONOMIC IMPACTS OF PROGRAMS TO SUPPORT CAREGIVERS:

FINAL REPORT

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Office of the Assistant Secretary for Planning and Evaluation

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ACRONYMS

The following acronyms are mentioned in this report and/or appendix.

ACA	Patient Protection and Affordable Care Act
ACL	Administration for Community Living
ADI-SSS	Alzheimer’s Disease Initiative-Specialized Supportive Services
ADL	Activity of Daily Living
ADRC	Aging and Disability Resource Center
ADSSP	Alzheimer’s Disease Support Services Program
ATUS	American Time Use Survey
CMS	Centers for Medicare & Medicaid Services
DME	Durable Medical Equipment
FMLA	Family and Medical Leave Act
HCBS	Home and Community-Based Services
HRS	Health and Retirement Study
IADL	Instrumental Activity of Daily Living
LTSS	Long-Term Services and Supports
NAC	National Alliance for Caregiving
NFCSP	National Family Caregiver Support Program
NHATS	National Health and Aging Trends Survey
NSOC	National Study of Caregiving
OECD	Organisation for Economic Cooperation and Development
SHARE	Survey of Health, Ageing and Retirement in Europe
SIPP	Survey of Income and Program Participation
SNAP	Supplemental Nutrition Assistance Program
SNF	Skilled Nursing Facility
TCARE	Tailored Caregiver Assessment and Referral
VA	U.S. Department of Veterans Affairs

INTRODUCTION

As the nation ages and more individuals live longer with chronic illness and disabilities (Freedman et al. 2013), the need for long-term services and supports (LTSS) will rise. Roughly 9.8 million Americans ages 65 and older living in settings other than nursing homes need care and help with personal activities, with 2.7 million requiring assistance with at least three basic activities of daily living (ADLs), such as bathing, dressing, or eating (Freedman and Spillman 2014). Additionally, many older adults suffer from poor mental health and cognitive impairment (Ormel et al. 2002; Kasper et al. 2014). Recent projections show that by 2065 the number of adults ages 65 and older with disabilities in the United States will increase about two and a half times from the current level, and more than half of Americans turning 65 today are expected to suffer from a disability that will eventually require LTSS (Favreault and Dey 2015).

An overwhelming majority of frail older Americans live in the community rather than in long-term care facilities, relying on family and friends for help and care. Only one in nine older adults receiving assistance lived in a nursing home in 2011 (Freedman and Spillman 2014). Ninety-five percent of older adults with LTSS needs living in a community setting received help and care from unpaid caregivers. In contrast, about 34 percent received some care from paid helpers, and only 5 percent relied exclusively on paid care. About three-quarters of total care hours received by non-institutionalized older persons are provided by unpaid caregivers (Spillman 2014).

These caregiving activities clearly benefit the economy. Without these unpaid services, many older adults would have to turn to paid helpers for assistance. Older adults with LTSS needs are more likely to enter nursing facilities, for example, if they do not receive family care than if they receive unpaid help from caregivers (Charles and Sevak 2005; Freeman 1996; Jette, Tennstedt, and Crasford 1995, Lo Sasso and Johnson 2002). Government programs, such as Medicaid, would have to cover some of the costs of additional paid LTSS, using state and federal funds.

Although family caregivers are not generally paid for their services, spending time helping family and friends with LTSS needs is often costly. Some caregivers may have to reduce their work hours when they provide care, switch to part-time work, or temporarily drop out of the labor force. Reduced work hours lead to lower earnings and may force caregivers to forfeit employer-sponsored health insurance (or shoulder a greater share of the premiums). Temporary labor supply reductions can have long-lasting repercussions, because people who leave their jobs often struggle to find alternative employment and must accept lower-paying positions. Lost earnings can also reduce future retirement income, as people are forced to save less for retirement (in 401(k) plans and other vehicles) and accumulate fewer Social Security credits. Reduced employment from caregiving can also have macroeconomic consequences, reducing government tax revenue and potentially slowing economic growth. Although it is well known that caregivers work less than people who do not provide care, this negative relationship does not necessarily imply that caregiving substantially reduces paid work hours. Instead, families may select non-employed members, or family members who work less than full-time, to provide care to elders with disabilities.

Government programs to support family caregivers could potentially limit some deleterious effects of caregiving. Programs that provide caregivers with training, counseling, information, and respite care or that provide care recipients with some paid help could relieve family caregivers, help them provide care more effectively, and perhaps enable them to increase their paid work hours. Support programs that enable caregivers to work more could in turn raise government tax revenue, partly offsetting part program costs.

This report assesses the number and characteristics of family caregivers, describes existing caregiver support programs, and gauges the potential macroeconomic impact of such programs. It explores the following research questions:

- How many people serve as family caregivers and what is their socioeconomic profile?

- How do caregiver employment and burden vary with the intensity of care provided and the presences of other caregivers who can help the care recipient?

- What are the potential macroeconomic benefits of government programs that support family caregivers?

The report begins with a review of the relevant literature on family caregivers and their caregiving experience, the economic impacts of caregiving, and existing programs and policies that support caregivers. Based on our literature review, an assessment of available data, and the needs of policymakers for information that can help them assess the economic impacts of caregiving, we develop a conceptual framework of caregiving decisions and their macroeconomic consequences and a typology of family caregivers that can guide our analysis. Using empirical estimates of the number and characteristics of family caregivers and assumptions drawn from the literature, we then gauge the potential macroeconomic impact of caregiver supports. Throughout the report, we define family caregivers broadly to include unpaid helpers who are friends and neighbors of care recipients as well as family members.

Our results show that relatively few caregivers provide intensive care, although these intensive caregivers are most likely to experience significant caregiver burdens and conflict between employment and care responsibilities. We conclude that the macroeconomic benefits of caregiver supports would likely be quite limited. Nearly one-third of family caregivers, and nearly one-half of family caregivers who provide intensive care without help from others, are ages 65 and older, and thus unlikely to work if they did not serve as family caregivers. The available empirical evidence suggests that relatively few younger caregivers would increase their labor supply much if they did not provide care. We found that the increase in earnings and tax revenue that might result from caregiver support programs would fall far short of the cost of providing those services.

LITERATURE REVIEW

This section reviews the relevant literature on family caregivers, describing what is known about the characteristics of caregiver and the economic impact of caregiving, including how caregiving affects paid employment. This review also describes activities, programs, and policies that support family caregivers and discusses assessments of their effectiveness.

Caregivers and Caregiving Experience in the United States

Unpaid caregivers, primarily family members, provide the vast majority of the LTSS received by older adults. Estimates of the number of family caregivers vary widely, mainly because of differences in the way various household surveys measure care provision. For example, surveys use different reference periods when collecting data on caregiving activities (i.e., the last month, the last 12 months, or the last two years), some collect caregiving data from caregivers while others collect data from care recipients, and some focus only on a primary caregiver. Consequently, estimates from nationally representative data collected over the past two decades of the number of adults providing care to people ages 65 and older range from 2.7 million to 36.1 million (Giovannetti and Wolff 2010). A 2015 study found that about 34 million adults--about one-sixth of the adult population--provided unpaid care to people ages 50 and older at some point in the previous year, including about 26 million caregivers who helped people ages 65 and older (NAC and AARP 2015). Spillman and colleagues (2014) estimated that about 18 million adults provided unpaid care to people ages 65 and older in the previous month.

While family caregiving is provided by a broad spectrum of caregivers, the burden of caregiving is not equally distributed across the United States population. Analyzing Health and Retirement Study (HRS) data, Butrica and Karamcheva (2014) found that 18 percent of married adults ages 51 and older provided care to their spouses at some point between 1996 and 2010, and 57 percent of adults ages 51 and older with surviving parents or parents-in-law provided care to them during that period. It is well established that spouses and adult daughters provide most of the unpaid care received by older adults (e.g., Johnson and Wiener 2006; Silverstein et al. 2006; Spillman and Black 2005; Spillman and Pezzin 2000; Wolff and Kasper 2006). According to 2011 National Health and Aging Trends Survey (NHATS) data, 47 percent of unpaid caregivers were the adult children--primarily daughters--of care recipients, 21 percent were spouses, 22 percent were other relatives, and the remaining 10 percent were non-relatives (Spillman et al. 2014).

Both the amount and duration of care vary significantly across caregivers. Spouses and other caregivers who live with older care recipients spend about 50 percent more time providing care than the average monthly amount of 75 hours (Spillman et al. 2014). A recent survey of caregivers conducted by the National Alliance for Caregiving (NAC) and AARP Public Policy Institute (2015) found that about half of family caregivers provided care for less than a year, while one-quarter provided care for at least five years.

An overwhelming majority of caregivers either lives with or within close proximity of care recipients (NAC and AARP 2015; Wolff and Kasper 2006). This is consistent with research that finds that geographic proximity is a key determinant of care provision and that adult children are more likely to live with a parent when that parent is disabled (Choi et al. 2015; Compton and Pollak 2009). There is some emerging evidence that the geographic proximity of older parents and adult children may vary by region and other characteristics of the locations where parents and their children live (Bui and Miller 2015; Compton 2015), although it is not clear how this geographic variation affects the availability of potential family caregivers. More than two-thirds of family caregivers to older adults are working-age, and about half of caregivers work for pay (Spillman et al. 2014). Spouses who provide care are much less likely to be employed than adult children who provide care because they are generally much older (Pinquart and Sorensen 2011).

Family caregivers perform a variety of support activities for older persons who need help with self-care or mobility (i.e., ADLs), various household activities corresponding to instrumental activities of daily living (IADLs), transportation, health system interactions (e.g., handling doctor appointments, ordering medicine), and health or medical care activities (e.g., diet and exercise, dental care, injections) (Spillman et al. 2014). Around two-thirds of adults age 65 and older who receive help from family caregivers suffer from long-term physical health problems, one-third experience memory-related problems or short-term physical health problems, and a substantial proportion suffers from emotional or mental health problems and behavioral issues (NAC and AARP 2015). Among family and unpaid caregivers to older non-institutionalized adults in NHATS, one-third of caregivers, and 41 percent of the hours of help they provide, help people with dementia, who account for about 10 percent of older non-institutionalized adults (Kasper et al. 2015). Family caregivers also play an important role in facilitating transitions between care settings (Levine et al. 2010), including successful transitions from long-term care facilities back to the community (Mudrazija et al. 2015), which are increasingly part of policy debate.

Almost seven in ten caregivers report substantial gains from caregiving, including satisfaction that recipients are well cared for and the realization that they are better able to deal with difficult situations, whereas only one in ten report experiencing substantial negative outcomes, such as exhaustion and the lack of time for themselves (Spillman et al. 2014). This is consistent with other findings from the recent literature that highlight some positive aspects of caregiving (e.g., Freedman et al. 2014; Bertrand et al. 2012).

Nonetheless, many caregivers describe feeling burdened by their care responsibilities. In the NHATS survey of older adults' caregivers, 15 percent of caregivers report substantial financial difficulties from providing care, 26 percent report substantial emotional difficulties, and 14 percent report substantial physical problems (Spillman et al. 2014). In another survey of adults who provide care to disabled adults regardless of age, 19 percent of caregivers reported high physical strain and 45 percent reported high stress levels; overall, 22 percent of caregivers indicated that their health was worse as a result of the care activities they performed (NAC and AARP 2015).[1] Compared to the general adult population, caregivers are more likely to report fair or poor health (17 percent versus 10 percent) (NAC and AARP 2015). Using data from the United Kingdom 2001 Census, Legg and colleagues (2012) found that caregiving was associated with poor health, especially for persons providing more than 20 hours of care per week. Even after adjusting for older adults' functioning and caregivers' and non-caregivers' sociodemographic and health characteristics, caregivers assisting with care coordination and medication management experience higher levels of financial, emotional, and physical health difficulties than non-caregivers (Wolff et al. 2016). Research also consistently shows that caregivers are more likely to suffer from depressive symptoms and mental health problems than non-caregivers (Marks et al. 2002; Pinquart and Sorensen 2003). In addition to a care recipient's health status (Spillman et al. 2014), the literature identifies several other factors that affect caregiver burden, such as the intensity of caregiving, the presence of competing time demands, the personal relationship between the caregiver and care recipient, and work-family conflict (Chappell and Reid 2002; Lin et al. 2012; Pearlin et al. 1990; Pinquart and Sorensen 2011; Spillman and Pezzin 2000; Zuba and Schneider 2013).

Economic Impacts of Caregiving

The high cost of paid LTSS, the limited availability of insurance covering those services, and personal preference all contribute to the current reliance on family caregivers. The median cost of a year of nursing home care in a semi-private room is now about $80,000 nationwide, and as much as 80 percent more in certain parts of the continental United States (Genworth 2015). The median hourly rate for home health aide services is $20, implying that the median cost of 90 hours of help per month--the median amount of paid help provided to recipients (Johnson and Wang forthcoming)--would total about $21,600 annually. Moreover, surveys consistently show that frail older people prefer living in the community than in institutions (Barrett 2014; Chapin et al. 2009; Reinhard 2010), but there are no dollar estimates of the value of better aligning older adults' preferences about care providers and care settings with the care they receive.

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[1] Caregivers in the NAC and AARP survey are younger than those in the NHATS survey. For example, only 19 percent of caregivers in the NAC and AARP survey are age 65 and older, compared with 32 percent in the NHATS survey.

Economic studies suggest that family caregiving reduces public and private spending on LTSS, including outlays on costly nursing facilities (Charles and Sevak 2005; Freeman 1996; Jette, Tennstedt, and Crawford 1995). Lo Sasso and Johnson (2002) found that frail older adults who receive frequent help from their children were about 60 percent less likely to enter a nursing home over a two-year period than those who received less help or no help at all.

Estimated Value of Family Caregiving

Estimates of the value of informal care for society vary substantially, primarily because of differences in how much each hour of care is valued, For example, using data from the American Time Use Survey (ATUS) Chari et al. (2015) peg the annual total value of unpaid care of older adults at $552 billion (or $412 billion if limited to caregivers younger than 65) when they value each hour at the caregiver's hourly wage (or an estimate of her hourly wage based on her characteristics if she is not employed). The estimated value falls to $221 billion when they value hourly care at the minimum wage and rises to $642 billion when they assume that unpaid care would be replaced by skilled nursing home care. Reinhard et al. (2015) estimate the value of care for persons with ADL limitations at $470 billion in 2013, deriving the underlying assumptions on average intensity of care and monetary value of an hour of care from a systematic analysis of relevant prior studies. Butrica and Karamcheva (2014) use HRS data and estimate that family caregivers ages 51-70 provided between $63 and $160 billion of care in 2010. Based on international Organisation for Economic Cooperation and Development (OECD) data, Yoo et al. (2004) conclude that family caregiving is related with slower growth in paid LTSS costs. However, none of these estimates accounts for the possibility that paid caregivers may be more efficient providers of care (i.e., that they could potentially provide the same service in less time, at least to some care recipients), and they disregard the possibility that care recipients might consume less care if they had to pay for it.

Moreover, these estimates ignore the potential social costs of family care provision, including the possible negative impact on the labor force participation, hours of work, and productivity of family caregivers, as well as caregiving-related physical and mental strain, which can reduce their taxable income and raise government outlays for income and health supports to caregivers. Consequently, assessing the net impact of family caregiving for the government and general public is difficult (Jacobs et al. 2013). Some estimates that attempt to take this broader perspective suggest that lost income tax payments and increased costs for social assistance for family caregivers may sometimes outweigh gains from reduced spending on paid care. Using Canadian data, Jacobs et al. (2013) estimate that high-intensity family caregiving (15 hours or more of care provided weekly) results in a net loss to the government of about $641 million, whereas low-intensity caregiving (five hours or less of care provided weekly) results in a net gain of about $4.4 billion. Similarly, Kok et al. (2015) find that unpaid home care in the Netherlands provides a net benefit to the (central) government when compared with the costs of paying for residential care, yet this government gain comes with net losses for older care recipients and their family caregivers, and, to a lesser extent, municipalities and health insurers.

Relationship between Caregiving and Employment

Estimates of the economic impact of family caregiving depend primarily on the accuracy of the underlying assumptions, especially when it comes to various costs of family caregiving that are difficult to assess. Among these, the most important and the most complex to measure is arguably the impact of family caregiving on caregivers' employment. It is well established that family caregivers work less--are less likely to work and work fewer hours when they are employed--than people of the same age who do not care for family members, although the differences are not particularly large. Butrica and Karamcheva (2014) found that 59 percent of women ages 51-70 who provided care to their parents with LTSS needs worked, compared with 61 percent of their counterparts who did not provide to their parents or in-laws. Moreover, it is not clear how much of caregivers' labor supply shortfall can be attributed to family caregiving activities. Caregiving could potentially reduce caregivers' labor force participation and, among those who remain employed, may lower work hours and productivity. Or, low-wage workers and people with limited labor force attachment, such as those who are not working or work only part-time, may be more likely to serve as caregivers than high-wage, full-time workers because their opportunity costs of providing care are low. In addition, an employed caregiver could choose to reduce time spent on various non-work activities rather than scale back work hours to accommodate their caregiving responsibilities. If partnered, a higher earning partner may increase his or her work effort to offset the lost income of the informal caregiver partner.

Empirical studies of how family caregiving affect labor market activity have employed various statistical methods to account for selection into caregiving roles. The most common approach has been to regress caregiving activities on labor market outcomes, such as paid employment, number of work hours, retirement decisions, or earnings, and control for observable characteristics of the sample of caregivers and non-caregivers that likely affect employment decisions, such as age, gender, education, race and ethnicity, marital status, and presence of young children.[2] Other studies have used more sophisticated techniques, such as instrumental variable models, simultaneous models, and structural models, that further attempt to control for unobservable differences between caregivers and non-caregivers that might influence employment outcomes.[3] For example, especially hardworking family members might be more likely to serve as caregivers as well as work for pay than people with less drive, or people with an especially strong devotion to their family might be more likely to serve as caregivers and less likely to work outside the home than people less committed to their families.

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[2] Examples of studies following this approach include Bittman, Hill, and Thomson (2007), Dentinger and Clarkberg (2002), Henz (2006), Lee and Tang (2015), Lilly, Laporte, and Coyte (2010), Pavalko and Artis (1997), Wakabayashi and Donato (2006), and Wakabayashi, Chizuko, and Donato (2015).

[3] Examples include Bolin, Lindgren, and Lundborg (2008), Butrica and Karamcheva (2014), Chen et al. (2015), Crespo and Mira (2014), Ettner (1995), Heitmuller and Inglis (2007), Johnson and Lo Sasso (2006), Nguyen and Connelly (2014), Skira (2015), Van Houtven, Coe, and Skira (2013), and Wolf and Soldo (1994).

Although research has confirmed the importance of controlling for observable characteristics when estimating the employment effects of family caregiving, several studies have concluded that there is little evidence that failing to account for unobservable factors biases estimates (Bolin, Lindgren, and Lundborg 2008; Butrica and Karamcheva 2014; Nguyen and Connelly 2014; Van Houtven, Coe, and Skira 2013). Consequently, the following discussion of the family caregiving and employment literature includes studies that did not account for the impact of unobservable factors, although all the studies and estimates described below held observable, non-caregiving factors constant when comparing employment outcomes for caregivers and non-caregivers or for different types of caregivers.

These studies reached mixed conclusions about the impact of family care on employment, with estimated effects varying by the caregiver’s sex and relationship to the care recipient, the intensity and type of care provided (such as personal care or help with household chores), and country. In the United States, several studies found that serving as a family caregiver significantly reduced the likelihood of paid employment among women, but the effects were generally small and evident only among women who spent a lot of time providing care. For example, Butrica and Karamcheva (2014) found that women ages 51-70 in the HRS who spent more than 1,000 hours per year caring for their parents were 3.4 percentage points less likely to work than women who devoted less time to caregiving or did not provide any care. Lee and Tang (2015), who examined a sample of women ages 51-61 in 2004 in the HRS, found somewhat larger impacts, but only for women who provided personal care to their parents. Van Houtven, Coe, and Skira (2013) also examined HRS data, but they did not find any significant employment differences between women ages 50-70 who provided care to their parents and those who did not, even among women who provided personal care or intensive care. Using longitudinal data from the National Survey of Families and Households, Wakabayashi, Chizuko, and Donato (2005) found that women who served as the primary caregivers for their parents with disabilities were more likely to leave the labor force than non-caregivers, but they found no significant effects for secondary caregivers. Some studies have concluded that middle-aged men who provide personal care to their elderly parents are less likely to work than men who do not provide care (Butrica and Karamcheva 2014; Van Houtven, Coe, and Skira 2013). Other types of parent care, such as help with household chores, does not appear to influence men’s employment changes, and relatively few men provide personal care to their parents. Labor force participation also appears to be more negatively affected if caregivers live with care recipients (Ettner 1995), suggesting that not living together may at least partly reflect the ability of employed caregivers to successfully balance paid work and caregiving responsibilities.

Many studies that examined caregivers outside the United States found larger and more consistent employment effects than those that examined United States caregivers. In a sample of Canadians ages 55-69, Jacobs et al. (2014) found that, compared with being a non-caregiver, providing intensive care--15 or more hours per week--is associated with more than twice the risk of retiring as opposed to working full-time for both men and women and that women are almost twice as likely to exit the labor force. Nguyen and Connelly (2014) focused on a sample of people ages 25-64 in Australia and found that being a primary caregiver reduces the probability of employment by about 12 percentage points for both men and women. Bolin et al. (2008) found that helping parents with both personal care and household chores significantly reduced employment probabilities for older European men and women, based on the HRS sister survey in Europe, SHARE. Crespo and Mira (2014) estimated much larger negative impacts on women's employment in Southern Europe (Italy, Spain, and Greece).

Results are also inconclusive with respect to work hours for caregivers who remain employed. Some evidence suggests that female workers reduce their work hours when they provide care to their parents. Johnson and Lo Sasso (2006), for example, used the 1996 and 1998 HRS data to assess possible changes in labor supply among women ages 55-67 who provided at least 200 hours of informal care to their parents over the study period, and found a decrease of 367 annual work hours, of which 174 arose from reduced work hours and the rest arose from decreased labor force participation. Based on HRS data from 1992 to 2008, Van Houtven et al. (2013) estimated that employed women ages 51-70 reduce their labor supply between three and ten hours per week when they provide care, but they found no reduction for men. Other studies, including Butrica and Karamcheva (2014) and Wolf and Soldo (1994) in the United States, Lilly et al. (2010) in Canada, and Bolin et al. (2008) in Europe, found little evidence that caregiving reduces labor hours.[4] Using British data, Henz (2006) suggested that the relationship between employment and caregiving may be quite nuanced and may differ by type of employment, with workers in routine and semi-routine occupations that may offer little workplace flexibility having to reduce their work hours more than other workers when they become caregivers.

The impact on employed caregivers' earnings is closely associated with the impact on hours worked and, accordingly, the estimates vary. Using British data on the working-age population, Heitmeuller and Inglis (2007) found that between 1993 and 2002 employed caregivers earned about 6 percent less, on average, than non-caregivers, but half of that difference could be attributed to caregivers' personal characteristics. In the United States, Van Houtven et al. (2013) found 3 percent lower wages for caregivers than non-caregivers, but only among women. Butrica and Karamcheva (2010) and Lilly et al. (2010) found no difference in wages for employed United States and Canadian caregivers relative to non-caregivers.

Another less studied aspect of employment-related impacts of caregiving is whether and how much caregiving activities may adversely affect work productivity. A recent survey suggests that more than 60 percent of employed caregivers had to make work adjustments that could impact their productivity, most commonly by adjusting their work schedule (e.g., coming late or leaving early) and taking time off, but also taking leaves of absence or switching to a less demanding job (NAC and AARP 2015). A few employed caregivers (7 percent) even reported receiving warnings about their job

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[4] Lilly et al. (2010) found that caregiving reduces labor hours for men providing at least 20 hours of care per week, but they make up only 3 percent of male caregivers and only 1 percent of all men ages 45-65.

performance and attendance (ibid). In a rare study that attempts to directly assess the impact of caregiving on work productivity, Mazanec et al. (2011) found that providing care to someone with advanced cancer might reduce work productivity by as much as 23 percent. These productivity losses translate into costs for employers and, ultimately, the economy. Some older estimates suggest that absenteeism, work interruptions, eldercare crisis, switching schedule from full-time to part-time, unpaid leave, finding replacement employees, and other employed caregiver related work situations cost United States business about $34 billion per year (Metlife Mature Market Institute and NAC 2006).

Work adjustments needed to accommodate caregiving responsibilities can reduce caregivers' pay and benefits. A survey suggests that even short job absences have significant financial ramifications for workers (Klerman et al. 2014). Among those taking a leave of absence under the Family and Medical Leave Act (FMLA), only 9 percent received full pay during their absence, while 16 percent received no pay. About 62 percent of leave takers with partial or no pay reported financial difficulties. Because most employees are required to pay their share of employer-provided health insurance during their absence regardless of whether they are being paid, insurance and medical expenses may further exacerbate their financial problems. As families draw down their savings and other resources, some may be forced to turn to social safety net programs (Gershuny 2012). In the long run, leaving the labor force to provide care can limit future employment, reducing retirement savings and later retirement income, including Social Security benefits (Butrica and Karamcheva 2014; Bolin et al. 2008; Crespo and Mira 2014; Ettner 1995; Favreault 2010; Favreault and Steuerle 2008; Pavalko and Artis 1997; Tamborini and Purcell 2015, Van Houtven et al. 2013). One estimate suggests that providing care to a frail parent may reduce lifetime earnings, Social Security benefits, and employer-provided pension benefits by more than $300,000 (MetLife Mature Market Institute 2011). Favreault et al. (forthcoming) projected that lifetime earnings lost by mothers in the 1976-1980 birth cohort because of caregiving activities average $281,000, but they attributed more than 90 percent of the loss to childcare, not eldercare; lost earnings from eldercare average only $24,000. A study using Australian data concluded that when education, health, and marital status are held constant, women who are primary caregivers to older persons with chronic health conditions or disabilities earn between 10 percent and 74 percent less over their careers than non-caregivers (Nepal, Brown, Ranmuthugala, and Percival 2011).

These negative impacts of caregiving on personal finances of caregivers can have social implications and may ultimately add to the cost for the government. For example, researchers have established that women providing care to older persons are more likely to fall into poverty (Butrica and Karamcheva 2014; Wakabayashi and Donato 2006). Using HRS data and controlling for selection, Wakabayashi and Donato (2006) estimated that women who provided at least 20 hours of care to parents in 1992 had a 27 percent higher likelihood of receiving any public assistance (Supplemental Security Income, Temporary Assistance for Needy Families, or Food Stamps Program, now Supplemental Nutrition Assistance Program [SNAP]) by 2000 than non-caregivers, and they were more than 46 percent more likely to be on Medicare.

Beyond the work-related impact of caregiving, physical and mental strain from caregiving may also have economic impacts. For example, caregiver strain may be adversely related with the risk of institutionalization of older care recipients. Simulations in Spillman (2014) suggest that reducing stress among caregivers could reduce expected nursing home days by about a third over 1 year, reducing nursing home costs by between $730 million to $1 billion.

Activities, Programs, and Policies to Support Caregivers

Various programs and policies directly support family caregivers or provide indirect support by helping care recipients. This section provides an overview of selected activities and related programs and policies that define the spectrum of available supports; it is not an exhaustive list of these programs and policies. For each type of assistance, we identify the programs that cover it and their scale, the caregivers that are targeted, and evidence on the economic impacts of the program (including any available evaluations).

Medical Leave

For employed caregivers, a critical source of support is provided through the provisions of the **FMLA**, as well as state-leave programs, employer-provided paid and unpaid leave programs, and temporary disability programs, among others. Although these programs and policies do not transfer resources directly to caregivers, they help many employed family caregivers balance their care activities with work. The FMLA guarantees unpaid leave of up to 12 weeks to care for a spouse, child, or parent, and up to 26 weeks to care for an injured member of the military. Other covered situations include personal health problems, pregnancy or birth of a child, adoption or the foster care placement of a child, and an exigency related to covered active military duty of an immediate family member. The program covers only workers employed for at least 12 months and 1,250 hours over the last 12 months at an employer with at least 50 employees. Whereas FMLA-covered leaves are taken primarily for employee’s own illness, about a fifth is related to family members’ (including older parents’) health problems (Klerman et al. 2014).

Several states, including California, Connecticut, the District of Columbia, Hawaii, Maine, Massachusetts, Minnesota, New Jersey, Oregon, Rhode Island, Tennessee, Vermont, Washington and Wisconsin, have their own leave laws that mandate more generous benefits than the FMLA (Han and Waldfogel 2003). California, New Jersey, and Rhode Island mandate paid leave, typically between one-half and two-thirds of normal pay (Jorgensen and Appelbaum 2014). Examples of other state-leave provisions include extended parental and maternity leave and limited unpaid leave for parents for school-related purposes. Most state-leave programs exclude workers at small employers.

A comprehensive evaluation completed in 2012 shows that about 13 percent of FMLA-covered employees took leave in the year preceding the survey (Klerman et al. 2014), which implies that about 2 percent of all covered workers took FMLA leave to care for ill family members. The evaluation suggests that the FMLA has benefited covered employees; only 5 percent reported an unmet need for leave, half of which stemmed from the unaffordability of unpaid leave. Very few employers reported that the FMLA reduces productivity or profitability. Moreover, studies suggest that the increased flexibility that the FMLA provides for a majority of employed family caregivers improves patient case management and patient outcomes (Swanke and Zeman 2009). However, FMLA coverage is far from universal. In 2012, more than 49 million workers--44 percent of the private sector workforce--were not eligible for FMLA benefits (Jorgensen and Appelbaum 2014).

Results from evaluations of paid family leave programs across several states that implemented them offer some limited evidence of their effectiveness, especially with respect to care for older family members. A survey of employers in California suggests that paid family leave either had no effect or a small positive effect on productivity and profitability (Milkman and Appelbaum 2013). An analysis of the impact of paid leave on family caregivers' labor market outcomes in California and New Jersey found no significant impact on leave-taking, employment, or labor force participation compared with states with no paid leave provisions (Morefield et al. 2016). The authors identify various potential hurdles to higher use of paid leaves by family caregivers, including lack of information and possible adverse consequences of taking a leave that is not job-protected. In addition, programs may not address the needs of family caregivers as well as those of other types of beneficiaries.

Respite Care

Respite care services benefit family caregivers by offering temporary relief from caregiving obligations, thereby allowing them to attend to personal and other needs without having to worry about care provision for their family member. Respite care includes a variety of services, including medical and social services to older adults and help with household chores, and it can be provided in different settings including homes, adult day care centers, and formal care institutions that allow for overnight stays. Accordingly, it can be categorized as in-home care, adult day care, and overnight respite (Whittier et al. 2001).

Respite care services are provided through various programs. As the major provider of **home and community-based services (HCBS)**, **Medicaid** is an important source of support for family caregivers.[5] It enables states to provide medical and non-medical services such as supports and service coordination, home health care,

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[5] Beyond HCBS, Medicaid can also support family caregivers by paying for various assistive technologies and home modifications (Doty and Spillman 2015), which may help caregivers complete their caregiving tasks.

personal care, adult day health services, and respite care to eligible people, primarily through waivers (i.e., 1915(c)). Providing such services as personal care aides and homemaker chore services for persons with functional disabilities offer respite for family caregivers (Doty and Spillman 2015). In fiscal year 2012, about half of the 1.5 million HCBS waiver enrollees were aged and disabled people, and they accounted for 21 percent (or $8.5 billion) of total HCBS waivers spending (Ng et al. 2015). In fiscal year 2014, the HCBS program provided about 36.5 million hours of assistance to older adults with ADL or IADL limitations through Personal Care, Homemaker, and Chore Services (ACL 2016c). In addition to HCBS waivers, states also provided HCBS services through home health state plan services and personal care state plan services, which together have about as many enrollees as the HCBS waivers. However, only people with very little income and nearly no assets quality for Medicaid.

Another important source of respite care is the **National Family Caregiver Support Program (NFCSP)**, established in 2000 through a reauthorization of the Older Americans Act. It provides grants to states (and territories) for respite care and other caregiver services such as counseling, support groups, and training.[6] Family caregivers of adults ages 60 and older or people of any age with Alzheimer's disease or a related disorder are eligible.[7] The program is administered in collaboration with Area Agencies on Aging and local community-service providers. While the program serves more than 900,000 caregivers, fewer than 70,000 receive respite care (ACL 2016c). However, with average annual spending of more than $1,300 per caregiver receiving respite care (Doty and Spillman 2015), they account for more than half of the program's budget, which has been around $150 million in recent years (ACL 2016c). In fiscal year 2014, NFCSP provided about 6.2 million hours of temporary relief to caregivers (ACL 2016c).

Medicare offers respite care as part of its **hospice benefits** (CMS 2016). An older adult's respite-related stay in a Medicare-approved facility (such as a hospice inpatient facility, hospital, or nursing home) can last up to five days and may be approved more than once. This benefit, however, is limited to terminally ill patients. Medicare also covers **home health services**, such as intermittent skilled nursing care, physical therapy, speech-language pathology, and continued occupational therapy services, for homebound adults. This services may help older adults remain in the community while relieving some of the care burden for informal caregivers, thereby effectively providing them with respite. Medicare expenditures on home health totaled $29 billion in 2014, including $18 billon for home health agencies that primarily provide skilled nursing services to patients (CMS 2015), representing an important, albeit indirect, source of respite.

Evaluations of respite care generally find that it is effective at reducing caregiving burden and improving caregivers' psychological well-being (e.g., Gaugler et al. 2003; Jeon et al. 2005; Shaw et al. 2009; Spillman and Long 2009), although this is not a

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[6] Respite care services are also provided through other programs serving certain populations, most notably veterans and Native Americans.

[7] Grandparents and other relatives (except parents) ages 55 and older providing care to children younger than 18 or adults ages 18-59 with disabilities are also eligible, but this report focuses on the older population.

universal finding (e.g., Chen et al. 2010). Respite care is more likely to be effective if the service is provided before substantial caregiving-related stress accumulates and if it is targeted to caregivers who provide intensive care for such conditions as dementia or stroke (Barber 2013). One recent study found that adult day services, which provide out-of-home, supervised, group services to people with LTSS needs, significantly improve caregivers' regulation of the stress hormone, cortisol, thus potentially improving caregivers' long-term health (Klein et al. 2016). However, there is no strong evidence that respite care delays care recipients' institutionalization or that it is more cost-effective than alternatives (e.g., Mason et al. 2007). The absence of more definitive findings on some aspects of respite care effectiveness appears to be related to the lack of controlled empirical studies (Jeon et al. 2005; Mason et al. 2007).

Other Caregiver Support Activities

Counseling, Training, Information and Referral Assistance

The major source of information and referral assistance, as well as counseling, support groups, and training for family caregivers is the **NFCSP**.[8] In 2014, of about 934,000 caregivers served by the program, almost 80 percent received only information and referral assistance, while an additional 13 percent received counseling and training services (ACL 2016c). Annual average spending per program participant receiving counseling support has been about $200 (Doty and Spillman 2015). Given the aforementioned average spending per participant receiving respite care services, this implies that average spending for the vast majority of program participants who primarily receive information and referral assistance is only about $50.

Studies that examine how counseling, training, and information and referral assistance affect caregivers and care recipients generally conclude that they are effective. These studies find positive effects of counseling (e.g., Drentea et al. 2006), training (e.g., Coon et al. 2003), and information and referral assistance (e.g., Weuve et al. 2000) on caregivers' well-being and care recipients' outcomes. Interventions that combine multiple services, such as counseling and support groups, appear to be especially effective (e.g., Gaugler et al. 2008).[9]

A major evaluation of NFCSP is currently underway. The first phase, which evaluated program processes, was recently completed, and it found a substantial increase in the number of services and supports available to family caregivers since the program began. For example, the share of Area Agencies on Aging offering caregiver support groups and training tripled, while the share offering counseling quintupled (Lewin Group 2016). Substantial gains were also observed for State Units of Aging. Providers, however, almost uniformly identified limited funding as one of the major

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[8] Similar to respite care services, programs serving veterans and Native Americans also offer these services. Some funding for caregiver training is also available at the state level through Medicaid HCBS waivers. For example, Indiana's waiver program allows recipients of Community Integration and Habilitation Waiver or Family Supports Waiver to use up to $2,000 of the allotted funding for caregiver training.

[9] For a more detailed overview of studies on various types of assistance available for family caregivers through NFCSP, see Barber (2013).

impediments to making continued gains in supporting family caregivers (Lewin Group 2016).

An evaluation of the expansion of the NFCSP program in Washington State in 2011 found that it reduced enrollment in Medicaid long-term care services among program recipients by 20 percent (Lavelle et al. 2014). An earlier assessment of the program in California also suggests positive impacts, including an increase in caregivers' utilization of support services and a corresponding decrease in their unmet needs, barriers to service use, and distress (Scharlach et al. 2006). Long and colleagues (2014) estimate that providing support services for caregivers of people with dementia in Minnesota could reduce spending between $100 million and $2.64 billion, primarily by reducing nursing home stays.[10]

Indirect Caregiver Support Activities

Medicare and Medicaid provide indirect support to caregivers through various services that are primarily designed to help older frail adults either remain at home or transition back to the community after a hospital or nursing facility stay. This support can supplement and facilitate the caregiving activities of family caregivers. For example, as noted earlier **Medicare** provides home health services for homebound older adults in need of skilled care. It also provides **post-acute care** for older adults, an important source of support for family caregivers during the transitional period following a hospital stay. This period is often critical, especially for inexperienced caregivers preparing both logistically and emotionally for their new role. In addition to home health services, Medicare-covered post-acute care is mostly provided through skilled nursing facilities (SNFs), with maximum coverage of 100 days per benefit period (i.e., a period that begins when a beneficiary is admitted to a hospital or SNF as an inpatient).[11]

Another important source of Medicare's support for family caregivers is coverage for **durable medical equipment (DME)**, such as walkers or wheelchairs, that can significantly improve a caregiver's ability to help a care recipient. In 2015, Medicare spending reached $30 billion for SNFs, $18 billion for home health agencies, and $6.5 billion for DME (Congressional Budget Office 2016; CMS 2015).[12]

Medicaid is increasingly supporting **self-directed service provision**, allowing beneficiaries more control over how they obtain home-based care services (Castora-Binkley et al. 2010). The main way in which self-direction supports family caregivers is by allowing them to become their relatives' paid aides. Alternatively, family caregivers may participate in selecting a paid aide--often other family members, friends, or neighbors--who enjoy their trust. As of 2013/2014, about 840,000 Medicaid

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[10] NFCSP evaluations across different states assess the overall impact of all aspects of the program including respite care.

[11] Some Medicare beneficiaries receive post-acute care in inpatient rehabilitation facilities and long-term care hospitals.

[12] Medicare provides some limited direct support to family caregivers by offering respite care as part of its hospice benefits (CMS 2016). An older adult's respite-related stay in a Medicare-approved facility (e.g., hospice inpatient facility, hospital, or nursing home) can last up to five days and may be approved more than once.

beneficiaries, at least half of whom were older adults, participated in this delivery model (Doty and Spillman 2015). A fraction of these care recipients (about 75,000) had budgetary authority that allowed them or their representatives to control the Medicaid funds allotted to them (Doty and Spillman 2015).

Other Caregiver Support Programs

Programs Supporting Caregivers of Various Subpopulations

Several programs providing direct assistance to caregivers target narrower populations. Most comprehensive among them are various supports and services provided by the **U.S. Department of Veterans Affairs (VA)** to caregivers of veterans. These include the Caregiver Support Line, the Caregiver Support Coordinator, the Caregiver Peer Support Mentoring Program, Adult Day Health Care Centers, Home-Based Primary Care, Skilled Home Care, the Homemaker and Home Health Aide Program, Home Telehealth, Respite Care, and Home Hospice Care. Caregivers of veterans who sustained serious injury in the line of duty after September 11, 2001, are entitled to monthly stipend and travel expenses while accompanying veterans undergoing medical care, health insurance if not already covered, mental health services and counseling, and caregiver training. In fiscal year 2015, nearly 25,000 individuals were approved as primary family caregivers of veterans, and $454 million was appropriated for caregivers' support (VA 2016).[13] The estimated cost for fiscal year 2016 is $622 million to cover about 30,600 caregivers.

The **Native American Caregiver Support Services** program provides support to persons of American Indian, Alaskan Native, and Native Hawaiian origin caring for older family members with chronic illness or disability and grandparents caring for grandchildren. Services include information and outreach, access assistance, individual counseling, support groups and training, respite care, and other supplemental services. In 2013, 37,568 people received information about services, 21,413 received assistance with access to services, 5,322 received individual counseling, 6,908 received caregiver training, 3,007 participated in support groups, 2,481 used lending closet,[14] and 6,233 received other types of support (ACL 2016d). Currently, the total cost of the program is $7.5 million (ACL 2016c).

Institutional Capacity Building Programs

Multiple programs that are aimed at supporting caregivers do not provide them with direct assistance, but rather are designed to offer support by building institutional capacity and investing in improving and better coordinating resources that are already available. While overall funding for institutional capacity building programs is much

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[13] Average spending per covered veteran caregiver was about $18,300 in 2015, which is substantially more than average spending per NFCSP beneficiary. However, direct comparison of the two programs is not necessarily possible since we lack information on possible differences in the LTSS needs of care recipients. Moreover, average NFCSP spending does not account for other possible sources of support that non-veteran caregivers may receive.

[14] The lending closet is a program that allows people to borrow DME either at little or no cost.

smaller than the funding for direct assistance to caregivers (and especially indirect assistance through public support for persons in need of long-term care), these programs are fundamentally different and cannot be directly compared.

The **Aging and Disability Resource Center (ADRC)** program is a joint effort of the Administration for Community Living (ACL) and the Centers for Medicare & Medicaid Services (CMS), and is a part of a "no wrong door" system. ADRC's stated goal is to "raise visibility about the full range of options that are available, provide objective information, advice, counseling and assistance, empower people to make informed decisions about their long-term supports, and help people more easily access public and private long-term supports and services programs" by providing a "single point of entry into the long-term supports and services system for older adults and people with disabilities" (ADRC 2014).[15] The program was initially implemented between 2003 and 2005 in 43 states and territories, and reached 49 states and territories in 2009, when a total of $11 million in grants was awarded. Since then, further grants were made to various states to develop Options Counseling Standards, implement and evaluate evidence-based Care Transition programs, and develop integrated and dementia-capable LTSS systems. In 2008, the Veterans Health Administration started using the ADRC to deliver the Veteran-Directed Home and Community-Based Services program. As a part of the broader health care reform effort, the Patient Protection and Affordable Care Act (ACA) provided $50 million dollars over 5 years for the development of the program. ADRC's 2016 budget exceeded $6 million (ACL 2016c).

Another example of a program aimed at supporting caregivers through improved institutional capacity is the **Lifespan Respite Care Program**. It supports implementation of community-based respite care services for family caregivers of children and adults of all ages with special needs. Some of its major initiatives include facilitating administration of federal respite care provider training, improving inter-agency coordination of respite care services, and developing registries of respite care providers, among others. In 2016, the budget for the program was about $3.4 million (ACL 2016c).

The **Alzheimer's Disease Support Services Program (ADSSP)** helps fund state efforts to increase the availability of supportive services at the community level for persons with Alzheimer's disease and dementia more generally. The program also supports implementation of successful evidence-based models into community-level practice, as well as efforts to coordinate public and private organizations that provide services to persons with Alzheimer's disease. In 2011, the Administration on Aging supported 80 ADSSP projects across the United States. A related initiative, Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS), has been implemented in recent years to address certain gaps observed in the original ADSSP, including

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[15] The use of information technology and the Internet in particular has significantly improved awareness of caregiver support programs and other resources available to informal caregivers. Although these resources do not represent support policies or programs in the traditional sense, they undoubtedly provide valuable help to caregivers of older persons.

behavioral symptom management training for family caregivers. In fiscal year 2016, the total budget for the two programs was $15.3 million: $4.8 million for ADSSP and $10.5 million for ADI-SSS (ACL 2016c).

In addition to these government-supported programs, various programs and initiatives are being developed in the private sector, targeted at improving the use of already available resources by increasing the efficiency of existing programs. One such example is the **Tailored Caregiver Assessment and Referral (TCARE)** care management protocol, designed to support people who are providing care for family members in need of assistance. Developed by researchers at the University of Wisconsin-Milwaukee, it is primarily aimed at care managers and professionals with the goal of facilitating the assessments of caregivers' needs, improving matching of appropriate services with caregivers' specific needs, and fostering informed client choice and person-centered care.

Thus far, TCARE has reached more than 20,000 caregivers through more than 250 community-based social and health service organizations and ten military installations across 17 states. For example, in Washington State TCARE was integrated into the existing NFCSP program, and a recent evaluation suggests that it contributed to a significantly lower likelihood that care recipients enrolled in Medicaid long-term care services in the 12 months following caregivers' first TCARE screening (Lavelle et al. 2014). The program has been evaluated through randomized trials and longitudinal studies (e.g., Kwak et al. 2011; Montgomery et al. 2011), and it was found to reduce caregiver stress and clinical depression, increase caregivers' positive feelings about caregiving, and potentially delay the institutionalization of care recipients. The program has also been reviewed by the ACL (ACL 2014).

Policy Proposals and International Comparisons

Although a broad range of programs provide direct or indirect support to caregivers, about a quarter of recently surveyed caregivers finds it very difficult to obtain affordable care-related services in their community (NAC and AARP 2015). Policy proposals that would provide financial supports to family caregivers include tax credits or deductions and direct payment for caregiving services. Higher-income caregivers generally prefer tax credits, whereas lower-income caregivers overwhelmingly prefer to be paid for their services (NAC and AARP 2015). In addition, Social Security caregiver credits could increase retirement incomes for family caregivers who take time out of the labor force. One recently proposed piece of legislation, the Social Security Caregiver Credit Act of 2014, would modify the Social Security benefit formula to credit individuals for each month in which they provided at least 80 hours of care to a dependent relative without financial compensation, for up to five years. Under current rules, Social Security credits individuals only for their time in paid work.

International comparisons show that developed countries use a variety of options to support family caregivers, such as providing support services (e.g., respite care, training, and counseling), implementing work-life balance policies (e.g., flexible work arrangements and work leave), and providing financial compensation through cash payments, tax incentives, and caregiver credits (Colombo et al. 2011). About two-thirds of OECD countries have policies supporting leave for caregivers, while less than half have paid leave for caregivers, mostly limited to a period of up to one month and/or terminal illness (Colombo et al. 2011). Family leave laws are a good example of cross-national variation in the size and scope of programs that may support family caregivers, ranging from unpaid leave in Germany and the United Kingdom (although the United Kingdom has payment options for persons who leave their job to become a caregiver) to fairly generous paid leave in Denmark, the Netherlands, and Spain (Yang and Gimm 2013). However, among the developed countries, the United States generally ranks low in policies that support family-work balance (Block et al. 2013).

CONCEPTUAL FRAMEWORK

Our conceptual framework of the provision of unpaid family care, shown in Figure 1, focuses on the decision for a particular potential family caregiver to help a particular potential care recipient. It highlights how public policy (including caregiver support programs) and various characteristics of the potential caregiver, care recipient, and other family members may influence the caregiving decision and how caregiving may shape macroeconomic outcomes, including economic growth, government revenues, and government expenditures. Rectangles in the figure represent characteristics of families or policies, and circles and ovals represent outcomes. Blue rectangles signify the potential caregiver's own characteristics, green rectangles signify characteristics of the potential care recipient and other family members, yellow rectangles signify public policies, red circles signify care outcomes, and purple ovals signify macroeconomic outcomes. Solid lines pointing from a characteristic to an outcome (or from one outcome or characteristic to another) indicate that the characteristic (or outcome) directly affects the particular outcome (or characteristic). Many solid lines point in both directions, indicating that they influence each other. Dashed lines from characteristics or outcomes to solid lines identify characteristics or outcomes that moderate the impact of one factor on another, strengthening or weakening the relationship.

A family member with LTSS needs may receive assistance from the potential care recipient, other family members, or paid helpers, as depicted by the three red circles in the center of the figure. Whether each of these sources provides assistance, and how much, affects the likelihood and amount of help from each of the other sources. We generally view these sources as substitutes, but it is not unusual for a care recipient to obtain help from all three or from none of them. In fact, many older adults with disabilities have substantial unmet needs. Nonetheless, more help from one source generally reduces the amount of help from other sources, when other factors (such as need) are held constant.

Personal Characteristics of the Potential Caregiver

The potential caregiver's own characteristics shape choices among these three types of care. One of the most important factors is whether the potential caregiver is employed. We postulate that employed adults are less likely to provide family care than those who do not work for pay, and that the provision of care reduces paid hours and the likelihood of paid employment (although the impact may be relatively small). Whether other family members provide care can influence this relationship. For example, help from family members may allow the primary caregiver to reduce the hours they spend providing care, enabling them to work more for pay. Help from family members can also allow primary caregivers to be more flexible with their care activities, because others can fill in for them when needed.

Our conceptual framework postulates that potential caregivers' financial status can influence care choices. Financial resources can help family members with LTSS needs purchase assistance. They can also influence the provision of unpaid care directly, by better enabling caregivers to cover some out-of-pocket costs associated with caregiving, such as housing coresident care recipients or traveling to non-coresident care recipients. Indirect effects of financial resources on unpaid care, operating through paid employment, may be more significant. Financial security may reduce the need to work, which can enable more care activities. Care choices also influence financial status, as unpaid care may indirectly reduce income by cutting paid work hours and directly raise out-of-pocket costs. Spending on paid LTSS for care recipients can deplete financial resources.

Other personal characteristics of the potential caregiver may also shape care choices. For example, competing family responsibilities such as the presence of minor children may affect time available to provide family care and financial resources that could be used to help cover paid LTSS. All these factors indirectly affect unpaid care from other family members through their impact on paid LTSS and family care from the potential care provider.

Characteristics of Care Recipients and Family Members

Our conceptual framework highlights the role of care recipient characteristics on family care. How much LTSS an older adult receives and who provides it depend on such factors as the care recipient's needs and financial resources. We postulate that care recipients will receive more paid LTSS, and thus somewhat less unpaid family care, as paid LTSS becomes more affordable, either because the recipient has substantial financial resources or qualifies for subsidized paid care through Medicaid (or some other potential program). The severity of their disability will help determine the amount and type of care they receive. Severe needs that necessitate round-the-clock care may likely require paid LTSS, whereas unpaid family care may be sufficient to meet less severe needs. Whether care needs are time-bound may also affect the type of care provided. Family caregivers likely have more difficulty meeting time-bound needs, such as personal care that must be provided at a particular time, than providing help with chores or errands that can be scheduled. The severity of LTSS needs likely moderates the impact of unpaid family care on caregivers' employment. Family care may interfere more with employment when caregivers are satisfying time-bound needs than when they helping with more flexible chores or errands.

The personal characteristics of other family members also influence care choices, in the way we described in the previous subsection. Paid employment makes unpaid family care less likely, and unpaid family care may reduce paid employment. Competing family responsibilities may also limit unpaid family care, and family members' financial status may help determine how likely they are to help cover paid LTSS expenses.

Role of Public Policy

The conceptual framework highlights two roles for public policy in shaping care choices--family caregiver supports and financing options for paid LTSS, depicted in yellow rectangles in the figure. As described earlier, family caregiver supports may make it easier for families to provide care to older adults with LTSS needs, raising the likelihood and amount of such care. If effective, these supports would moderate the relationship between family care and paid employment, reducing the negative impact of one on the other by making it easier for caregivers to remain in the labor force and for workers to provide family care. By sustaining family care, these programs could also delay entry of older care recipients into paid LTSS, such as costly nursing facilities.

The availability and generosity of financing options for paid LTSS could also affect family decisions about paid LTSS, in turn influencing the amount of family care that is provided. Public policies that subsidize paid care or that promote private insurance coverage for paid care could increase the receipt of paid LTSS, perhaps reducing unpaid family care.

Macroeconomic Impacts

Family care decisions can have important macroeconomic consequences, affecting economic growth, government revenue, and government expenditures, depicted by the purple ovals in the figure. By potentially limiting paid employment, family care can directly reduce government revenue from income taxes and payroll taxes and shrink the labor force, which could lower economic growth and further reduce tax revenue. Family caregiving activities can potentially limit caregivers' earnings so much that they qualify for needs-based government support, such as Medicaid, SNAP benefits, or health insurance premium subsidies through the ACA, raising government expenditures. Receipt of certain types of paid LTSS, such as nursing home care, can also raise government expenditures, because Medicaid is the single largest payer of nursing home costs. To the extent that family care can delay nursing home entry, family care decisions can also influence government expenditures.

Programs to support family caregivers can shape macroeconomic outcomes, as highlighted in our conceptual framework. By promoting unpaid family care and limiting its negative impact on paid employment, family caregiving supports can raise employment and earnings, boosting economic growth and government tax revenue. Government expenditures on paid LTSS subsidies could also fall if family caregiver supports enable older adults with LTSS needs to remain longer in the community and defer paid LTSS. The government cost of family caregiver supports at least partially offset these gains, however. Other government expenditures might crowd out funding for caregiver supports or paid LTSS financing.

Caregiver Typology

Although research on family care to older adults and its implications for care recipients, caregivers, and the overall economy has been growing, relatively few studies attempt to classify caregivers into policy-relevant categories that could guide future policy efforts. Earlier efforts to categorize caregivers have generally focused on various aspects of the care burden (e.g., Di Rosa et al. 2011; Jegermalm 2006; Porter et al. 2004). The literature has identified the following major elements that seem most relevant to economic analyses of the impact of family caregiving:

- Characteristics of care activities, including type (i.e., complex tasks such as those related to functional disability, or simpler tasks such as help with household chores), frequency, intensity, and duration.
- Caregiver resources (support network availability, public support services) and competing demands on time (labor market attachment, young children).
- Care recipient’s caregiving needs and available resources (personal income and wealth; public health and social care services).
- Caregiver-care recipient relationship and geographic proximity.

Most existing categorizations and related analyses, however, are based only on a limited subset of these elements, which in turn limits their usefulness for assessing of economy-wide impacts of family caregiving.

Our conceptual framework suggests a typology of family caregivers to identify people who likely experience substantial care burdens, particularly those that create potential conflict between caregiving and competing time demands, such as employment. An ideal typology would reflect the following factors:

- Type of care needed (time-bound such as support with personal care activities or non-time-bound such as help with household chores).
- Intensity of care (intensive vs. non-intensive).
- Family support (whether the caregiver functions alone or is part of a broader caregiving network).
- Duration of care (long-term vs. temporary).

The type of care that is necessary often reflects the care recipient’s cognitive status. Whether the recipient has dementia could be an additional element in the typology.

The data requirements for implementing this typology are daunting. The typology requires information on care activities, the care recipient’s disability status and cognitive functioning, and the full network of available family caregivers. Longitudinal or detailed retrospective data would also be necessary to characterize the duration of care. And the sample would have to be sizable so that researchers would have enough observations in each category to conduct meaningful analysis. The following section describes a simplified typology that we can implement with available data.

DATA AND METHODS

The overarching goal of our analysis is to estimate the number of family caregivers who might benefit from caregiver support programs and to assess the potential macroeconomic impact of such programs. We explore the following research questions:

- What is the total size of the population of family caregivers and the prevalence of family care to older adults in the United States? What is the socioeconomic profile of family caregivers?
- How do employment and income profiles differ across different types of family caregivers? How does caregiver burden differ, measured by both subjective assessments of financial and physical difficulty as well as objective measures, such as absenteeism related to work-caregiving conflict?
- What are the potential macroeconomic benefits of government programs that support family caregivers?

Data Source: National Study of Caregiving

To generate nationally representative estimates of the number of family caregivers ages 65 and older, describe their characteristics, examine the challenges they face, and assess the potential benefits of programs designed to help them, we used data from the 2011 wave of the National Study of Caregiving (NSOC), a supplement to the first round of the NHATS.[16] The NSOC interviews a sample of family caregivers to NHATS respondents, who in turn make up a nationally representative sample of Medicare beneficiaries ages 65 and older.[17] Of the 4,935 family caregivers identified by 2,423 NHATS respondents, the survey successfully collected data on 2,007 caregivers, who cared for 1,369 NHATS respondents. Sample weights account for non-response as well as differential probabilities of selection into the sample. Our final analytic sample was further limited to family caregivers who were age 15 or older and who reported providing care to the NHATS respondents in the month prior to the interview (N=1,995).[18]

The NSOC, in combination with the NHATS, is particularly well-suited for this study. They provide detailed information on both caregivers and care recipients across

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[16] For the calculations of prevalence of informal caregiving by selected characteristics in the overall population we supplemented the NSOC data with the appropriate Census Bureau's annual estimates of the resident population in the United States.

[17] The survey interviewed up to five family caregivers for each NHATS respondent, randomly selecting five caregivers when a respondent reported having six or more family caregivers.

[18] We imputed data for 146 family caregivers with missing information on the exact hours of care provided to the NHATS respondents and/or missing age. We used multiple imputation by chained equations to impute the missing values.

all the dimensions necessary to examine the impact impacts of caregiving. In addition, the entire (or nearly entire) network of family caregivers, rather than a single caregiver (typically the primary caregiver) or some small subset of caregivers, which better allows us to assess the full range of caregiver burdens.

However, some features of this data set may limit our analysis and conclusions. By design, the NHATS is a nationally representative annual longitudinal survey of Medicare beneficiaries ages 65 and older, which excludes a relatively small number of older adults who do not qualify for Medicare and people below the age-eligibility threshold.[19] Furthermore, in Round 1 the NSOC collected information on only about 41 percent of the family caregivers initially eligible for interview. In many cases, then, full information on the personal characteristics of all caregivers in a caregiving network is not available. Although NSOC generally offers much more detailed information on family caregivers than other surveys, some important information is missing, such as the racial and ethnic background of family caregivers. Consequently, NSOC is not well-suited to analyses focused on estimating the prevalence of caregiving in the population and how it varies among certain subgroups. The survey also lacks information on caregivers' employment history, preventing a careful assessment of the lifetime effects of informal caregiving on labor force attachment, type of employment, and work intensity. Finally, we had access to only one wave of interviews when we completed the data analysis. The NSOC conducted the second round of data collection in 2015, four years after the initial survey, and those data are now available. However, given the survey design and the time elapsed between interview waves, it is not clear how much information the second NSOC wave can provide on caregiver dynamics.

Other surveys that collect data on caregivers have serious shortcomings. The HRS collects longitudinal information on help provided to parents, parents-in-law, and spouses, but only interviews people age 51 or older, excluding a significant portion of the caregiver population. The Disability and Use of Time study, a supplement to the Panel Study of Income Dynamics, is quite small, and the ATUS collects data on only a single caregiver. The Survey of Income and Program Participation (SIPP) asks respondents whether they provided "regular unpaid care or assistance" to a family member or friend with a "long-term illness or a disability." The ambiguity of those terms appears to reduce estimates of caregiving prevalence. Our exploratory analysis revealed a much lower prevalence of caregiving among SIPP respondents than implied nationally by the NSOC. Moreover, less-educated, lower-income SIPP respondents were less likely to report providing care than their better-educated, higher-income counterparts, contrary to the pattern found in other surveys and casting further doubt on the reliability of the SIPP care data. In addition, the Census Bureau substantially revised the SIPP for the 2014 panel, eliminating the informal caregiving topical module, so subsequent waves of SIPP data will not provide any information on family caregivers.

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[19] Medicare covers all adults ages 65 and older (as well as people with disabilities), except for those who did not meet the program's work requirement and are not married to someone who met the work requirement, and foreign-born people who are neither United States citizens nor permanent residents.

Developing a Tractable Typology

We developed a simplified typology that could be implemented with the NSOC data. Because we had access to only one wave of data, we dropped duration of caregiving activity from our typology. We also factored in the size of the family caregiver network--the number of family caregivers--which we considered to be a critical characteristic that can affect both the amount and flexibility of care provision by any individual family caregiver. These considerations led to the following typology of family caregivers:

A. Sole caregiver:
   1. Time-bound and intensive care.
   2. Other intensive care.
   3. Non-intensive care.

B. Multiple caregivers:
   1. Time-bound and intensive care.
   2. Other intensive care.
   3. Non-intensive care.

The distinction between intensive and non-intensive care is, of course, somewhat arbitrary. We classified care that averaged ten hours or more per week as intensive and other care as non-intensive.[20]

This typology is both sufficiently parsimonious and flexible to allow us to show how caregiver burdens vary across caregivers. It allows us to focus on the characteristics of caregivers that most influence caregiver burdens and the economic impact of caregiving on caregivers as identified in the conceptual framework. These characteristics, in turn, can help us determine how caregiving burden varies across populations with similar levels of caregiving responsibilities, thereby allowing for a comprehensive and nuanced classification of family caregivers. We will focus on variables that are most directly related with the actual or potential competing demands on caregivers' time--their work status and related characteristics, including hours worked (full-time vs. part-time) and

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[20] On average, part-time workers in the United States work 21 hours (Ruggles et al. 2015). Full-time workers are usually defined as persons who work 35 hours or more per week, and data show that about two-thirds of full-time workers work up to 40 hours per week (Bureau of Labor Statistics 2016). Therefore, an average part-time worker who provides family care for a minimum of ten hours per week or more has a combined time commitment (i.e., employment and caregiving) approaching that of a full-time worker without caregiving responsibilities. Our results are robust to using a higher cutoff point (i.e., 20 hours of care per week) for intensive informal caregiving, albeit the proportion of persons categorized as intensive caregivers decreases.

Another possible adjustment relates to the geographic proximity of caregivers and care recipients. Although all family caregivers generally live relatively close to the care recipient, non-coresident caregivers must spend time traveling to and from the care recipients' residence, which may increase their care burden relative to coresident caregivers who provide the same level of care. However, our analysis suggests that including travel time in tabulations of total time spent on caregiving activities does not substantively impact the estimates of the number of caregivers providing intensive and non-intensive care.

the flexibility of their work schedule; presence of minor children;[21] and marital status (although we recognize that having a spouse can represent both a competing time demand and a source of financial, physical, and emotional support). Additionally, we will distinguish caregivers by their key demographic characteristics such as age (with a focus on working-age vs. older caregivers), sex, and the caregiver-care recipient relationship (e.g., spouse or partner, parent-child, other family, friends/non-family), as well as their socioeconomic status, which may relate to objective or subjective perceptions of caregiving burden. Based on the intersection of these various characteristics with the basic categorization of caregivers, we should ultimately be able to identify groups of caregivers that are most likely to face the highest burden of caregiving as well as those whose caregiving activities may have the highest opportunity cost.

Using information from the NHATS tracker file, we further classified each family caregiver as either a sole caregiver or a caregiver who belongs to a family support network with multiple caregivers.

Methods and Measures

We estimated the number of caregivers by type and described their characteristics. Following our new typology, we classified caregivers by the type and intensity of care they provided--intensive self-care or mobility care, other types of intensive care, and less intensive care--and whether they were the sole caregiver for a care recipient or part of a broader care network. Intensive care was defined as ten or more care hours per week. Our sample included caregivers ages 15 and older who helped Medicare beneficiaries ages 65 and older. However, we restricted the sample to caregivers ages 20-64 when we examined work-caregiving conflict, because employment rates are quite low for people outside this age range. We generated national estimates of the share of people who provide care to older adults by using NSOC sample weights to estimate the number of caregivers by sex and age group and dividing those estimates by the Census Bureau’s annual estimates of the resident population for selected age groups by sex for the United States (including Puerto Rico) for 2011.

Our tabulations profile caregivers, reporting for each caregiver type the average number of monthly hours spent providing care; the distribution of age, sex, income, education, and relation to care recipient; Medicaid enrollment; health status; and employment status. Health problems were measured by overall self-rated health status (excellent, very good, good, fair, or poor), and the presence of chronic health conditions (history of heart attack or other heart disease, arthritis, osteoporosis, diabetes, lung disease, and cancer). We classified caregivers as anxious or depressed if they reported that they had “little interest or pleasure in doing things,” “felt down, depressed, or hopeless,” “felt nervous, anxious, or on edge,” or had “been unable to stop or control

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[21] Although an increasing proportion of children ages 18 and older lives with parents, data limitations prevent us from exploring alternative definitions of dependent children.

worrying" nearly every day or more than half the days over the past month. Full-time employment was defined as working at least 35 hours per week.

Our tabulations highlight some of the challenges that caregivers face. We computed the share of caregivers who reported that helping a care recipient was financially, physically or emotionally difficult and who said that the statement, "You have more things to do than you can handle," described their situation. We measured work-caregiving conflict as working at a job that did not offer flexible work hours, in that they could not vary their work hours or make changes in the time they begin and end work. Finally, we computed the share of caregivers who took time off from work over the past month to help the care recipient.

Gauging the Potential Macroeconomic Impact of Caregiver Supports

We combined our estimates of the number of caregivers and their characteristics with findings from the literature to gauge the potential macroeconomic impact of caregiver support programs. As noted earlier, the potential macroeconomic consequences of family care for older adults result primarily from reducing employment of caregivers and lowering (or delaying) paid LTSS for family care recipients. However, our analysis of the macroeconomic consequences of caregiver supports focused on employment effects because there is little evidence that caregiver support programs affect care recipients' use of paid LTSS (Mason et al. 2007; Vandepitte et al. 2016). We considered only family caregivers who were younger than age 65, because older people are much less likely to work, even when they are not providing care.

The first step in our approach was to estimate lost wages associated with family caregiving. Based on findings from Nguyen and Connelly (2014), we assumed that 12 percent of non-employed caregivers would have worked if they had not provided care. We considered this estimate, which exceeds others in the literature, an upper bound on the likely impact of caregiving on employment. We assumed that intensive caregivers would have worked full-time if they had not provided care and less intensive caregivers would have worked part-time. The analysis assigned 2015 average earnings for full-time workers within sex, education, and age groups, as estimated from the Annual Social and Economic Supplement of the Current Population Survey, to those caregivers who we assumed would otherwise have worked full-time, and average earnings for part-time workers to those caregivers who we assumed would otherwise have worked part-time. We further assumed, based on Van Houtven et al. (2013), that all caregivers employed part-time would have earned 3 percent more if they were not caregivers. To estimate these additional earnings, we assumed that caregivers earned averaged earnings for part-time workers within sex, education, and age groups.

The second step was to estimate the additional federal income and payroll tax revenue that these increased earnings would generate. We assumed that workers with at least a four-year college degree are in the 25 percent federal income tax bracket and that others are in the 15 percent tax bracket. We included the 2.9 percent Medicare payroll tax (split equally between employees and their employers), but we did not factor in the Social Security payroll tax because part of those revenues are offset by additional future Social Security benefits.

These estimates show how much earnings and tax revenue is lost by family caregiving activities. To estimate the potential impact of caregiver support programs, we assume that supports would enable some fraction of caregivers who reduced their labor supply when they provided care to return to work or work more. Because of the inherent uncertainty of the possible impact of support programs on caregiver labor supply, we estimated a range of possible effects. Our low estimate assumes no impact on employment, because there is no conclusive evidence that these supports increase employment. Our intermediate estimate assumes that support programs would restore one-tenth of the earnings lost to family caregiving, and our high estimate assumes that support programs would restore two-tenths of lost earnings.

RESULTS

This section reports our results, which describe caregivers, their employment status, their health status, and the caregiving burdens they face. It also reports estimates of earnings lost as a result of caregiving activities and the potential macroeconomic impact of caregiving support programs.

Prevalence of Caregiving by Selected Characteristics

In 2011, 7.2 percent of people ages 15 and older--about 18 million individuals--provided informal care to adults ages 65 and older (Table 1).[22] The likelihood of serving as a caregiver generally increased with age. At ages 15-64, 5.8 percent of the population provided informal care, compared with 13.9 percent of the population ages 65 and older. The likelihood of providing care peaked at 15.1 percent at ages 65-79. Nonetheless, about one in ten adults ages 80 and older served as unpaid caregivers to older adults. Among adults ages 20-64, who are most likely to be employed, 6.4 percent provided informal care.

Women were more likely to provide informal care to older adults than men, although the difference in prevalence rates was not dramatic because the overall prevalence rate was quite low. Among adults ages 15 and older, 8.7 percent of women and 5.7 percent of men served as caregivers. The gender gap grew with age until traditional retirement ages; at ages 50-64, women were about 7 percentage points more likely than men to serve as informal caregivers. At ages 80 and older, however, men were much more likely than women to provide care. Most older caregivers help their spouses, and older men are more likely than older women to have a survivor spouse that needs care.

Caregiving Network

Most informal caregivers are part of a network of unpaid helpers. In 2011, only about a fifth of caregivers--about 3.8 million people--were the only source of care for their care recipient, and only a tenth of caregivers provided intensive care alone (Table 2). Moreover, sole caregivers who provided intensive self-care or mobility care accounted for only about 4 percent of all caregivers. More than half (58.1 percent) of informal caregivers provided less than ten hours of care per month, and the vast majority of these less intensive caregivers were part of a care network.

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[22] This estimates are consistent with estimates from Spillman et al. (2014).

Intensity of Caregiving

On average, caregivers provided 74 hours of care each month (or about two and one-half hours per day), including 35 hours of self-care or mobility care. The intensity of care varied widely across our typology of caregivers. Providers of intensive self-care or mobility care (defined as ten or more hours per week) averaged 243 monthly care hours for sole caregivers and 217 monthly care hours for caregivers in a care network. Monthly averages were about 100 hours less for intensive providers of other types of care. By contrast, less intensive caregivers averaged only 17 hours of care per month.

The sex and age breakdown of caregivers varied by caregiver type. Overall, women accounted for about six in ten caregivers (Table 3). The caregiver gender gap was even larger among sole caregivers who provided intensive self-care or mobility care, 71 percent of whom were women. About two-thirds of caregivers were younger than age 65, including about four in ten who were ages 50-64. However, older adults accounted for more than half of sole caregivers; 49 percent of sole caregivers providing intensive self-care and mobility care and 57 percent of sole caregivers providing less intensive care were ages 65 and older. By contrast, only 23 percent of providers of intensive self-care or mobility care who were part of a care network were ages 65 and older.

Sole caregivers of older adults tended to be older than members of a care network because they were generally married to the care recipient. Overall, spouses or partners accounted for only 21 percent of all people caring for older adults, whereas children of the care recipient accounted for 54 percent of caregivers. However, spouses accounted for about half of sole intensive caregivers. By contrast, about six in ten members of care networks were the children of the care recipient.

Financial Status of Caregivers

Intensive informal caregivers tended to have less income than caregivers who provided less care (Table 4). Among members of care networks, average annual household income in 2011 was $37,800 for providers of intensive self-care or mobility care, compared with $61,600 for less intensive caregivers. Intensive caregivers were also more likely to live in poverty. Among sole informal caregivers, 25 percent of intensive self-care and mobility care providers had household incomes below the poverty line, compared with 7 percent of less intensive caregivers. Intensive caregivers were less likely than less intensive caregivers to have completed high school or to have earned a bachelor’s degree. They were also more likely to be enrolled in Medicaid.

Employment Status of Caregivers

Almost six in ten caregivers ages 20-64 were employed (Table 5). In 2011, 40 percent were employed full-time and 18 percent were employed part-time. Another 9 percent were unemployed in 2011, when the unemployment rate was unusually high. Less intensive caregivers were more likely to work for pay than intensive caregivers; 50 percent of care network members who provided less intensive care were employed full-time and 17 percent were employed part-time. Nonetheless, about three in ten care network members who provided intensive care and two in ten sole caregivers who provided intensive care were employed full-time.

The NSOC survey responses suggest that eldercare responsibilities sometimes interfere with paid employment. Nearly half of caregivers employed full-time had inflexible work schedules, including 52 percent of sole caregivers providing intensive self-care or mobility care. Only 17 percent of caregivers employed full-time reported that their care responsibilities forced them to miss work, but reported absences were much more common among intensive caregivers, especially those who provided care alone. Among sole caregivers employed full-time, 49 percent of those providing intensive self-care or mobility care and 31 percent of those providing other types of intensive care reported missing work because of their care responsibilities. The median amount of lost work time among caregivers reporting a care-related work absence was 8 hours per month overall, but 12 hours per month for sole caregivers who provided intensive self-care or mobility care.

Because relatively few caregivers were engaged in intensive caregiving activities, only a small share of informal caregivers to older adults provided intensive care that interfered with employment (although some non-employed caregivers might have chosen to work for pay if they did not serve as caregivers). In 2011, only 2.8 percent of caregivers ages 15 and older were employed, were the only caregiver for their care recipient, and provided intensive care, while 12.3 percent of caregivers ages 15 and older were employed and provided intensive care as part of a care network (Table 6). Intensive caregivers who provided care alone and were employed full-time with inflexible work schedules made up only 0.6 percent of all unpaid caregivers ages 15 and older, while sole intensive caregivers employed full-time who experienced a care-related work absence accounted for only 0.5 percent. Considering all intensive caregivers together, regardless of the size of the care network, we found that only 5.7 percent of caregivers provided intensive care and worked full-time with an inflexible job schedule and only 2.9 percent of caregivers provided intensive care while working full-time and missed work to provide care.

Health Status of Caregivers and Caregiver Burdens

Intensive caregivers tended to have more health problems than less intensive caregivers. Twenty-eight percent of sole caregivers who provided intensive self-care or mobility care and 25 percent of care network members who provided intensive self-care or mobility care described their overall health as fair or poor, compared with 19 percent of providers of less intensive care (Table 7). Overall, 58 percent of caregivers reported a chronic health condition, and 28 percent reported two or more conditions. Although the prevalence of chronic health conditions was higher among intensive caregivers who provided care alone than less intensive caregivers, the differences were not large. Health status varied most among caregivers for emotional well-being. Thirty-nine percent of sole caregivers providing intensive self-care or mobility care reported depression or anxiety, compared with only 17 percent of sole caregivers providing less intensive care.

Caregiver burdens were fairly common. Burdens were most prevalent among caregivers who provided intensive self-care and mobility care and less prevalent among caregivers who provided less intensive care. Burdens did not differ much between sole caregivers and members of care networks, conditional on the intensity of care provided. More than four in ten providers of intensive self-care and mobility care reported physical or financial difficulties from providing care, more than five in ten reported emotional difficulty, and about six in ten reported that their caregiving activities are very difficult or somewhat difficult to handle.

Few caregivers engaged in intensive care activities and experienced significant care burdens or health problems. Although 43.1 percent of all caregivers reported in 2011 that their care responsibilities were very or somewhat difficult to handle, intensive caregivers who provided care alone and reported such burdens accounted for only 4.7 percent of all caregivers (Table 8). In addition, intensive caregivers who were part of a care network and reported such burdens accounted for 16.9 percent of all caregivers.

Intensive caregivers who experienced employment conflicts or significant care burdens made up only a miniscule portion of the overall population. Caregivers employed full-time accounted for about 2 percent of the population ages 15 and older in 2011 (Table 9). Less than 1 percent of the overall population ages 15 and older provided eldercare while working full-time with an inflexible job schedule, and only about 0.3 percent provided eldercare, worked full-time, and missed work because of their care responsibilities. Only 119,000 people served as intensive caregivers who provided care alone and were employed full-time with inflexible work schedules, making up less than 0.1 percent of the age 15 and older population.

Turning to physical and emotional burdens of care, we found that only 4 percent of the population ages 15 and older provide eldercare and had a chronic health condition (Table 10). Moreover, only 3 percent of people ages 15 and older reported that caregiving created emotional difficulties for them or was too much for them to handle. Intensive caregivers who provided care alone and reported that their care responsibilities were very or somewhat difficult to handle accounted for less than 0.3 percent of the population. Table A1 reports the number of people in each caregiver category.

Potential Economic Benefits of Caregiver Supports

We estimated that, at most, family caregivers forfeited $28.3 billion in earnings in 2015 because of their caregiving activities (Table 11). Although this is a substantial amount, it represents only 0.3 percent of the $8.1 trillion of earnings collected economy-wide in 2015.[23] We estimated that most of the lost earnings came from caregivers who did not work at all, rather than from caregivers who worked part-time and might have worked more if they did not provide care. Caregivers ages 50-64 who attended college and provided intensive care accounted for one-third of lost earnings. Although male caregivers made up only 30 percent of this group, they accounted for 45 percent of the earnings lost by this group because average full-time earnings were about 50 percent higher for men ages 50-64 than for their female counterparts. Earnings lost in 2015 by caregivers employed part-time or not working averaged $4,100, but reached $12,100 for male caregivers ages 50-64 who attended college and provided intensive care.

The estimated impact of caregiver supports on earnings and tax revenues were much smaller, according to our estimates. Under our intermediate assumption of the impact of caregiver supports on earnings, we estimated that caregiver supports could raise total earnings by $2.8 billion, or $406 for every caregiver potentially affected (i.e., working part-time or not employed) (Table 12). The estimated earnings impact rose to $5.7 billion, or $812 per potentially affected caregiver, under our high-impact assumption, and fell to zero under our low-impact assumption. By comparison, the average annual cost of respite care is about $1,300 per caregiver (Doty and Spillman 2015), suggesting that policymakers could raise caregiver incomes more by providing them with cash payments than by funding respite care that could increase caregivers' hours of paid employment.

The estimated impact of caregiver supports on federal tax revenue was even smaller. We estimated that caregiver supports could raise federal tax revenue from the individual income tax and from the Medicare payroll tax by $1.4 billion if caregiver supports had a large impact on caregiver earnings and by $700 million if supports had an intermediate impact on earnings. The average impact per caregiver potentially affected would be $202 and $101, respectively. These estimates are much lower than the typical per caregiver cost of respite care programs. Under our low-impact assumption, caregiver supports would not generate any additional federal tax revenue.

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[23] We estimated total economy-wide earnings from the 2016 Current Population Survey, which underreports total earnings because the survey undersamples people with very high earnings.

CONCLUSIONS

Family caregivers provide invaluable assistance to older adults with disabilities, improving the quality of their lives and allowing many to live independently and delay or avoid expensive nursing facility care. Intensive caregiving responsibilities, however, can overwhelm some caregivers. They can create physical and emotional health problems and interfere with paid work activities. Public policies designed to support family caregivers can ameliorate these burdens and make unpaid caregivers more effective. They can also have macroeconomic benefits, if they enable caregivers to increase their paid work hours or if they reduce paid LTSS. Reducing paid LTSS could, in turn, trim LTSS spending by the Federal Government, which pays for a large share of LTSS costs through Medicaid. However, we need better information about the number and characteristics of intensive caregivers to evaluate the costs and benefits of such initiatives.

We developed a conceptual framework of caregiving that highlighted the key determinants of the family caregiving decision and the potential impacts on caregivers, care recipients, government costs and revenues, and economic growth. It emphasizes the interaction of family care with paid care, received either at home or in residential facilities, and employment decisions. Care activities affect employment decisions, but employment decisions also affect care activities. Although it is well established that family caregivers are less likely to be employed than non-caregivers, people may not necessarily reduce their labor supply when they begin providing care; instead, families may select non-employed members, or family members who work less than full-time, to provide care to elders with disabilities. Moreover, many caregivers work for pay, reducing their leisure time instead of their labor supply when caregiving demands arise. To the extent that care activities reduce employment, support programs that help caregivers accommodate paid work activities could boost government tax revenue, partially offsetting the cost of such programs. By relieving caregiver stress and physical demands, support programs could also reduce caregivers’ health expenditures, some of which are subsidized by federal and state governments through Medicare and Medicaid.

To identify those family caregivers who could benefit most from support programs, we developed a caregiver typology based on our conceptual framework that could be implemented with existing data sets. The availability of nationally representative data on caregiving is limited. Surveys that ask respondents about their caregiving experiences generally collect only limited information about care recipients, while surveys that ask respondents about the care they receive generally collect only limited information on the characteristics of their caregivers. For example, the HRS, which surveys adults ages 51 and older, asks respondents whether they provide unpaid help to their parents or in-laws and whether they receive unpaid help from family members or friends. However, the survey includes few questions about respondents’ family members, providing little information about care recipients for respondents providing care or care providers for respondents receiving care.

The best available data on caregivers and their care recipients come from the NSOC, which interviews unpaid caregivers of NHATS respondents. Because these linked surveys interview both care recipients and care providers, they provide detailed information about both generations of the care relationship. However, the NSOC design does not allow us to fully distinguish between short or intermittent episodes of caregiving and long and continuous provision of care. Multiple longitudinal waves of NSOC data could help fill this gap, since researchers could track caregivers over time and measure the persistence of care activities. Although the second wave of NSOC data, matched to the 2015 NHATS wave, was released in late 2016, it was not designed as a longitudinal follow-up to the first wave, thereby limiting its capacity to answer the questions that cannot be resolved with a single wave of data. In addition to strengthening the longitudinal aspect of the survey, it would be useful if the NSOC tracked all caregivers in the baseline NSOC wave, regardless of their subsequent caregiving activities, so researchers could explore such questions as why caregivers stop providing care and how the cessation of care activities affects the well-being of one-time caregivers.

Available data sets also make it difficult to assess the prevalence of care activities within the general population. The few surveys that ask a nationally representative sample of respondents whether they provide unpaid care to family members sample only a subset of the general population (such as adults ages 51 and older), ask only about a subset of caregiving activities (such as help to parents or in-laws), or ask imprecise care questions that appear to understate the true prevalence of such activities. We estimated the share of the overall population that provides care by using the sample weights in the NSOC. However, those sample weights rely on underlying assumptions about the prevalence of caregivers in the population made by the Johns Hopkins University researchers who conducted the survey.

Our analysis of NSOC data revealed that only a small share of caregivers, and an even smaller share of the population, face significant work-caregiving conflicts. However, some caregivers might have stopped working to accommodate their care responsibilities. In 2011, only 18.6 percent of caregivers ages 20-64 worked full-time with an inflexible job schedule, and only 6.5 percent worked full-time and missed work to provide care. Most of these caregivers provided less intensive care; only 5.7 percent of caregivers provided intensive care and worked full-time with an inflexible job schedule and only 2.9 percent of caregivers provided intensive care while working full-time and missed work to provide care. Moreover, less than 1 percent of the overall population ages and older provided eldercare while working full-time with an inflexible job schedule, and only about 0.5 percent provided eldercare, worked full-time, and missed work because of their care responsibilities.

Our analysis suggests that the macroeconomic benefits of caregiver supports would likely be quite limited. Nearly one-third of family caregivers, and nearly one-half of family caregivers who provide intensive care without help from others, are ages 65 and older, and thus unlikely to work if they did not serve as family caregivers. The available empirical evidence suggests that relatively few younger caregivers would increase their labor supply much if they did not provide care. Although there is little evidence on the effectiveness of caregiver supports, our best guess is that caregiver supports would raise total earnings by no more than $5.6 billion and federal income tax and Medicare payroll tax revenue by no more than $1.4 billion. On average, these supports would raise earnings by no more than $812 per caregiver and tax revenue by no more than $202 per caregiver, much less than the typical cost of providing a caregiver with respite care services.

However, caregiver supports can benefit caregivers in other ways, besides boosting their earnings. Programs that provide training and respite care could reduce stress and improve overall well-being for caregivers, especially the relatively small number who provide intensive care to family members and often appear to be overwhelmed by their care responsibilities. Compared with less intensive caregivers, these intensive caregivers are more likely to miss work because of their care obligations, experience more health problems, and are more likely to report that their caregiving activities are difficult to handle.

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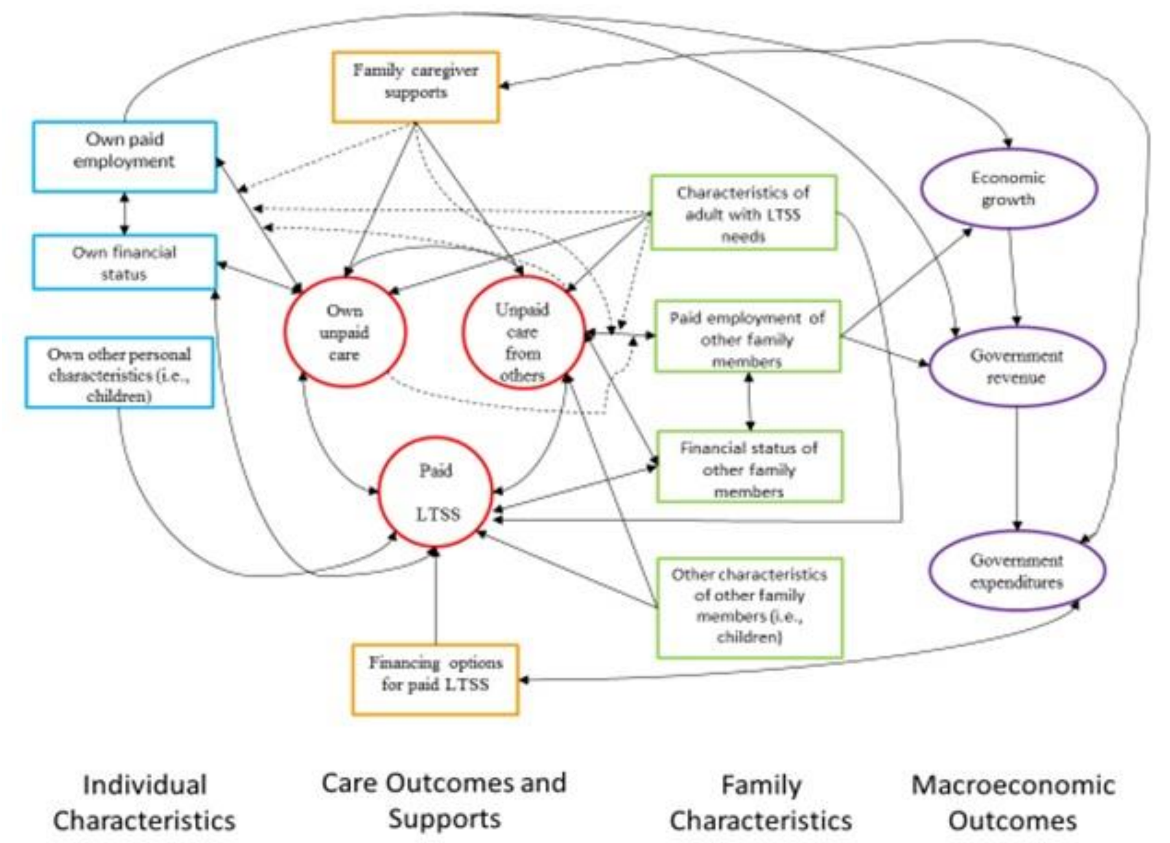
FIGURES

FIGURE 1. Conceptual Framework of Decision to Provide Unpaid Care and Its Consequences



TABLES

TABLE 1. Prevalence of Caregiving by Age and Sex, 2011 (%)

Age	All	Female	Male
All	7.2	8.7	5.7
15-64	5.8	7.5	4.1
15-34	1.6	1.9	1.3
35-49	5.6	7.1	4.1
50-64	11.7	14.9	8.2
20-64	6.4	8.2	4.5
65 and older	13.9	13.6	14.3
65-79	15.1	16.1	14.0
80+	10.7	8.1	15.3

SOURCES: Authors' estimates based on the NSOC and the U.S. Census Bureau's annual estimates of the resident population for selected age groups by sex for the United States, 2011.

TABLE 2. Demographic Characteristics and Medicaid Enrollment of Informal Caregivers Age 15 and Older, 2011

		Sole Caregivers				Member of Care Network			
	All Caregivers	All	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care	All	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care
Number of caregivers (thousands)	17,941	3,831	650	1,118	2,063	14,109	2,017	3,732	8,360
Percentage of caregivers	100.0	21.3	3.6	6.2	11.5	78.6	11.2	20.8	46.6
Average no. of care hours provided per month									
Total	74	93	243	130	17	69	217	103	17
Self-care/ mobility	35	48	154	17	8	32	125	18	7

SOURCE: Authors' estimates based on the NSOC.

TABLE 3. Demographic Characteristics of Informal Caregivers Ages 15 and Older, 2011

	All Caregivers	Sole Caregivers			Member of Care Network		
		Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care
Sex (% total for caregiver category)							
Male	38	29	34	45	37	33	40
Female	62	71	66	55	63	67	60
Average age (years)	58	63	62	65	54	54	57
Age distribution (% total for caregiver category)							
15-64	68	51	53	43	77	74	73
15-34	*7*	*2*	*5*	*4*	*12*	*12*	*6*
35-49	*20*	*8*	*17*	*5*	*28*	*24*	*20*
50-64	*41*	*41*	*30*	*34*	*37*	*38*	*47*
65 and older	32	49	47	57	23	26	27
65-69	*25*	*41*	*33*	*47*	*15*	*20*	*22*
80 and older	*7*	*8*	*14*	*10*	*7*	*7*	*5*
Relationship to care recipient (% total for caregiver category)							
Spouse/partner	21	51	52	44	20	17	11
Child	54	39	39	34	60	59	59
Other, family	16	9	6	16	17	18	17
Other, non-family	9	1	4	6	3	6	13

SOURCE: Authors' estimates based on the NSOC.

TABLE 4. Household Income, Education, and Medicaid Enrollment of Informal Caregivers Ages 15 and Older, 2011

	All Caregivers	Sole Caregivers			Member of Care Network		
		Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care
Average annual household income ($)							
All caregivers	53,500	48,600	41,300	61,400	37,800	44,800	61,600
Non-spouse caregivers	55,000	40,500	33,600	61,400	38,200	45,600	63,900
Distribution of household income relative to FPL (% total for caregiver category)							
Less than 100%	20	25	27	7	33	30	14
100-199%	23	21	21	25	30	25	20
200-400%	29	28	34	36	24	22	31
More than 400%	28	27	19	32	13	23	35
Education (% total for caregiver category)							
Not high school graduate	14	20	22	10	20	17	10
High school graduate	26	24	29	23	30	29	25
Vocational/Some college/Associate degree	33	38	31	37	30	35	32
Bachelor's degree or higher	27	18	18	30	20	20	33
Medicaid enrollment (% total for caregiver category)							
No	90	87	82	94	83	84	94
Yes	10	13	18	6	17	16	6

SOURCE: Authors' estimates based on the NSOC.
NOTE: Average incomes are rounded to the nearest $100. FPL=federal poverty line.

TABLE 5. Employment Characteristics of Informal Caregivers Ages 20-64, 2011

	All Caregivers	Sole Caregivers			Member of Care Network		
		Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care
Work status (% total for caregiver category)							
Employed	58	37	43	64	47	49	67
Full-time	*40*	*19*	*20*	*43*	*32*	*30*	*50*
Part-time	*18*	*18*	*24*	*21*	*15*	*19*	*17*
Unemployed	9	9	18	8	13	11	7
Out of the labor force/inactive	21	28	24	14	25	29	16
Retired/stopped working	12	26	16	13	14	10	10
Average hours of work (among employed caregivers)	36	33	30	35	34	34	38
Non-flexible work schedule							
% of all employed caregivers	43	40	34	40	37	43	45
% of caregivers employed full-time	46	52	56	36	41	48	47
Absent from work for caregiving							
% of all employed caregivers	15	38	24	10	21	19	12
% of caregivers employed full-time	17	49	31	16	27	18	13
Median monthly hours of absence for care (conditional on absence)	8	12	7	8	10	8	8

SOURCE: Authors' estimates based on the NSOC.

TABLE 6. Prevalence of Employment, Employment-Caregiving Conflict, and Caregiver Type among Informal Caregivers, 2011

percentage of caregivers who being to a given caregiver category and report being employed or experiencing an employment-caregiving conflict

	Total	Sole Caregivers			Member of Care Network		
		Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care
Employed caregivers							
% of caregivers ages 15 and older	44.3	0.9	1.9	4.2	4.3	8.0	24.9
% of caregivers ages 20-64	58.4	1.0	2.1	4.7	6.0	10.8	33.7
Full-time employed caregiver							
% of caregivers ages 15 and older	28.7	0.4	0.7	2.5	2.9	4.6	17.6
% of caregivers ages 20-64	40.4	0.5	1.0	3.2	4.0	6.7	25.0
Full-time employed caregiver with non-flexible work schedule							
% of caregivers ages 15 and older	13.2	0.2	0.4	0.9	1.1	2.2	8.2
% of caregivers ages 20-64	18.6	0.3	0.5	1.2	1.7	3.2	11.7
Full-time employed caregiver who had absence from work for caregiving							
% of caregivers ages 15 and older	4.4	0.2	0.3	0.3	0.7	0.8	2.2
% of caregivers ages 20-64	6.5	0.3	0.3	0.5	1.1	1.2	3.2

SOURCE: Authors' estimates based on the NSOC.

TABLE 7. Health Status and Caregiver Burdens, Informal Caregivers Ages 15 and Older, 2011

percentage of caregivers in each caregiver category reporting a health problem or caregiver burden

		Sole Caregivers			Member of Care Network		
	All Caregivers	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care
Health Status							
Fair or poor self-rated health	20	28	17	19	25	22	19
Any health condition	58	66	65	63	61	53	56
Two or more health conditions	28	34	33	30	26	29	27
Depression or anxiety	24	39	27	17	35	31	18
Caregiver burdens							
Physical difficulty	23	44	29	21	43	27	14
Financial difficulty	23	41	31	15	45	30	13
Emotional difficulty	44	54	51	44	58	48	38
Caregiving very difficult to handle	17	24	19	14	28	18	14
Caregiving very or somewhat difficult to handle	43	57	42	34	61	48	38

SOURCE: Authors' estimates based on the NSOC.
NOTE: Health conditions include heart attack or other heart disease, arthritis, osteoporosis, diabetes, lung disease, and cancer.

TABLE 8. Prevalence of Health Problems, Caregiver Burdens, and Caregiver Type among Informal Caregivers Ages 15 and Older, 2011

percentage of caregivers who belong to a given caregiver category and reporting a health problem or caregiver burden

		Sole Caregivers			Member of Care Network		
	Total	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care
Fair or poor self-rated health	20.4	1.0	1.1	2.2	2.8	4.6	8.6
Any health condition	57.5	2.4	4.1	7.2	6.9	10.9	26.0
Two or more health conditions	28.0	1.2	2.0	3.4	3.0	6.0	12.4
Depression or anxiety	23.6	1.4	1.7	1.9	3.9	6.4	8.4
Physical difficulty	22.9	1.6	1.8	2.4	4.8	5.6	6.6
Financial difficulty	22.8	1.5	1.9	1.7	5.1	6.3	6.3
Emotional difficulty	44.3	1.9	3.2	5.1	6.6	10.0	17.6
Caregiving very difficult to handle	17.1	0.9	1.2	1.6	3.1	3.7	6.5
Caregiving very or somewhat difficult to handle	43.1	2.1	2.6	3.9	6.9	10.0	17.6

SOURCE: Authors' estimates based on the NSOC.
NOTE: Health conditions include heart attack or other heart disease, arthritis, osteoporosis, diabetes, lung disease, and cancer.

TABLE 9. Prevalence of Employment, Employment-Caregiving Conflict, and Caregiver Type in the Overall Population, 2011

percentage of the population who belong to a given caregiver category and report being employed or experiencing an employment-caregiving conflict

	Total	Sole Caregivers			Member of Care Network		
		Intensive Self-Care/ Mobility Care	**Intensive Other Care**	**Less Intensive Care**	**Intensive Self-Care/ Mobility Care**	**Intensive Other Care**	**Less Intensive Care**
Employed caregivers							
% of population ages 15 and older	3.17	0.07	0.14	0.30	0.31	0.58	1.79
% of population ages 20-64	3.72	0.07	0.14	0.30	0.38	0.69	2.15
Full-time employed caregiver							
% of population ages 15 and older	2.06	0.03	0.05	0.18	0.21	0.33	1.26
% of population ages 20-64	2.57	0.03	0.06	0.20	0.26	0.42	1.59
Full-time employed caregiver with non-flexible work schedule							
% of population ages 15 and older	0.94	0.02	0.03	0.07	0.08	0.16	0.59
% of population ages 20-64	1.18	0.02	0.03	0.07	0.11	0.20	0.75
Full-time employed caregiver who had absence from work for caregiving							
% of population ages 15 and older	0.32	0.01	0.02	0.02	0.05	0.06	0.15
% of population ages 20-64	0.42	0.02	0.02	0.03	0.07	0.08	0.21
Median monthly hours of absence for care (conditional on absence, age 15+)	8	12	7	8	10	8	8

SOURCE: Authors' estimates based on the NSOC and the U.S. Census Bureau's annual estimates of the resident population for selected age groups for the United States, 2011.

TABLE 10. Prevalence of Health Problems, Caregiver Burdens, and Caregiver Type in the Overall Population Ages 15 and Older, 2011

percentage of the population who belong to a given caregiver category and reporting a health problem or caregiver burden

	Total	Sole Caregivers			Member of Care Network		
		Intensive Self-Care/ Mobility Care	**Intensive Other Care**	**Less Intensive Care**	**Intensive Self-Care/ Mobility Care**	**Intensive Other Care**	**Less Intensive Care**
Fair or poor self-rated health	1.46	0.07	0.08	0.16	0.20	0.33	0.62
Any health condition	4.12	0.17	0.29	0.52	0.49	0.78	1.87
Two or more health conditions	2.01	0.09	0.15	0.25	0.21	0.43	0.89
Depression or anxiety	1.69	0.10	0.12	0.14	0.28	0.46	0.60
Physical difficulty	1.64	0.11	0.13	0.17	0.35	0.40	0.47
Financial difficulty	1.63	0.11	0.14	0.12	0.37	0.45	0.45
Emotional difficulty	3.18	0.14	0.23	0.36	0.47	0.72	1.26
Caregiving very difficult to handle	1.22	0.06	0.08	0.11	0.22	0.27	0.47
Caregiving very or somewhat difficult to handle	2.93	0.11	0.15	0.19	0.51	0.68	1.29

SOURCE: Authors' estimates based on the NSOC.
NOTE: Health conditions include heart attack or other heart disease, arthritis, osteoporosis, diabetes, lung disease, and cancer.

TABLE 11. Estimated Earnings Lost from Family Caregiving

	Total	Women								Men							
		Intensive Care				Non-intensive Care				Intensive Care				Non-intensive Care			
		Ages 22-49		Ages 50-64		Ages 22-49		Ages 50-64		Ages 22-49		Ages 50-64		Ages 22-49		Ages 50-64	
		Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College
Number of family caregivers (thousands)																	
Not employed	4,868	346	386	467	555	225	114	305	898	278	83	192	297	83	106	193	339
Employed part-time	2,098	76	206	153	257	2	188	223	399	63	70	50	45	40	56	89	180
Median earnings																	
Full-time		33,300	63,700	40,500	74,700	33,300	63,700	40,500	74,700	46,000	91,600	54,700	113,300	46,000	91,600	54,700	113,300
Part-time		15,700	24,800	16,900	27,100	15,700	24,800	16,900	27,100	16,100	29,600	21,500	47,800	16,100	29,600	21,500	47,800
Percentage of non-employed caregivers assumed to work if they were not caregivers		12	12	12	12	12	12	12	12	12	12	12	12	12	12	12	12
Number of workers added to the labor force in absence of caregiving (thousands)																	
Part-time	273					27	14	37	108					10	13	23	41
Full-time	312	41	46	56	67					33	10	23	36				
Additional earnings from these workers ($ millions)	26,663	1,365	2,930	2,268	5,005	424	347	625	2,977	1,518	916	1,258	4,079	161	385	495	1,960
Additional earnings that caregivers employed part-time might earn if not providing care ($ million)	1,629	36	154	78	209	1	140	113	324	30	62	32	65	19	49	58	258
Total earnings lost from caregiving ($ millions)	28,291	1,401	3,084	2,346	5,214	425	487	738	3,251	1,548	978	1,290	4,144	180	434	552	2,218
Average earnings lost per caregiver employed part-time or not working ($)	4,100	3,300	5,200	3,800	6,400	1,900	1,600	1,400	2,500	4,500	6,400	5,300	12,100	1,500	2,700	2,000	4,300

SOURCE: Authors' computations.
NOTE: See text for a discussion of methods and assumptions.

TABLE 12. Estimated Impact of Caregiver Supports on Earnings and Tax Revenues

	Total	Women								Men							
		Intensive Care				Non-intensive Care				Intensive Care				Non-intensive Care			
		Ages 22-49		Ages 50-64		Ages 22-49		Ages 50-64		Ages 22-49		Ages 50-64		Ages 22-49		Ages 50-64	
		Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College	Did Not Attend College	Attended College
Number of family caregivers (thousands)																	
Not employed	4,868	346	386	467	555	225	114	305	898	278	83	192	297	83	106	193	339
Employed part-time	2,098	76	206	153	257	2	188	223	399	63	70	50	45	40	56	89	180
Total earnings lost from caregiving ($ millions)	28,291	1,401	3,084	2,346	5,214	425	487	738	3,251	1,548	978	1,290	4,144	180	434	552	2,218
Potential additional earnings from caregiver support ($ millions)																	
High	5,658	280	617	469	1,043	85	97	148	650	310	196	258	829	36	87	110	444
Intermediate	2,829	140	308	235	521	42	49	74	325	155	98	129	414	18	43	55	222
Low	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Potential additional earnings per caregiver from caregiver support ($)																	
High	812	665	1,042	756	1,284	374	323	280	501	907	1,274	1,069	2,418	293	538	390	854
Intermediate	406	332	521	378	642	187	161	140	251	454	637	534	1,209	146	269	195	427
Low	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Potential additional tax revenue from caregiver support ($ millions)																	
High	1,409	50	172	84	291	15	27	26	181	55	55	46	231	6	24	20	124
Intermediate	705	25	86	42	145	8	14	13	91	28	27	23	116	3	12	10	62
Low	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Potential additional tax revenue per caregiver from caregiver support ($)																	
High	202	119	291	135	358	67	90	50	140	162	355	191	675	52	150	70	238
Intermediate	101	59	145	68	179	33	45	25	70	81	178	96	337	26	75	35	119
Low	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

SOURCE: Authors' computations.
NOTE: See text for a discussion of methods and assumptions.

APPENDIX

TABLE A1. Number (in thousands) of Caregivers Ages 15 and Older by Type, Employment Status, Employment-Caregiving Conflict, Health Problems, and Caregiver Burdens, 2011

	Total	Sole Caregivers			Member of Care Network		
		Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care	Intensive Self-Care/ Mobility Care	Intensive Other Care	Less Intensive Care
Employed caregivers	7,936	165	342	749	773	1,443	4,474
Full-time employed caregiver	5,140	73	127	447	518	834	3,152
Full-time employed caregiver with non-flexible work schedule	2,355	43	76	170	202	394	1,475
Full-time employed caregiver who had absence from work for caregiving	814	31	46	60	131	147	398
Fair or poor self-rated health	3,656	181	195	396	497	833	1,551
Any health condition	10,322	427	727	1,299	1,231	1,964	4,673
Two or more health conditions	5,028	222	365	619	530	1,070	2,221
Depression or anxiety	4,242	250	298	344	700	1,147	1,499
Physical difficulty	4,101	287	328	426	865	1,006	1,188
Financial difficulty	4,101	269	342	306	918	1,127	1,125
Emotional difficulty	7,957	349	571	910	1,178	1,796	3,151
Caregiving very difficult to handle	3,063	156	212	288	560	671	1,174
Caregiving very or somewhat difficult to handle	7,738	373	472	702	1,232	1,793	3,162

SOURCE: Authors' estimates based on the NSOC.
NOTE: Health conditions include heart attack or other heart disease, arthritis, osteoporosis, diabetes, lung disease, and cancer.