Invisible Overtime: What employers need to know about caregivers

By Debra Lerner, MSc, PhD Tufts Medical Center, Program on Health, Work and Productivity Tufts Clinical and Translational Science Institute



INTRODUCTION

Family caregiving is part of the fabric of life both nationally and globally. At some point in our lives, many of us will become family caregivers, assisting a loved one who needs help as a result of illness, disability or aging. Caregiving comes in many different forms, involving many different types of assistance and many different definitions of family.

Like other aspects of family life such as parenting, family caregiving roles and responsibilities intersect with those from other life domains. One domain is employment. In recent decades, there have been significant changes in family caregiving and employment that have far-reaching implications for caregivers and their families, communities, businesses and the nation. Since the 1990's (when statistical tracking began), the United States (US) has seen growth in the number of people engaged in family caregiving, the number of weekly hours they provide assistance, the difficulty of their caregiving tasks and their labor force participation rate. In contrast to previous generations when caregiving was mainly provided by stay-at-home mothers, wives and daughters, today tens of millions of family caregivers are employed, and most are working full-time. Family caregivers are our coworkers, managers, corporate executives, business owners, clients and customers. They hail from all industries and all geographic areas. When they are not working at a paying job, family caregivers typically are spending hours providing assistance or arranging for assistance and, in many cases, they are unable to hire additional help. These working caregivers, whom we will refer to as Caregiver Employees (CEs) are the focus of this white paper.

It is clear from research that family caregivers need help. Employed or not, family caregivers exhibit high rates of physical, emotional, and financial strain. These strains are related to the demands of caregiving. These demands include assisting with activities of daily living such as maintaining personal hygiene and preparing meals and instrumental activities of daily living such as managing finances, tracking medical claims and navigating the healthcare system. Increasingly, caregivers also are being asked to perform medically oriented tasks often with little or no training. Family caregivers themselves appear to be in poorer health than comparable non-caregivers and many do not seek medical help or engage in self-care. Finally, they are often burdened with paying out-of-pocket expenses not covered by insurance.

The root causes of the growth in the number of CEs are not going away anytime soon. Like many other industrialized nations, the US is faced with an increasingly aging, chronically ill and disabled population. At the same time, more people are choosing to live out their later years at home in the community rather than in institutional settings. Additionally, more women than ever are in the labor market. Many families simply can't find affordable, high quality long-term care or home care alternatives. While the results of the COVID 19 pandemic on caregiving remain to be seen, is it reasonable to predict that the number of CEs will continue to grow.

As this white paper will discuss, family caregivers face challenges maintaining both caregiving and work roles and these challenges are costly. Recent reports have sounded the alarm to alert key stakeholders to the pressing need to better understand what is happening at the intersection of family caregiving and employment, and take action (Ding et al., 2020); (Fuller & Raman, 2019); (Body, 2020). However, because there are large gaps in information

It is clear from research that family caregivers need help. Employed or not, family caregivers exhibit high rates of physical, emotional, and financial strain.

about CEs and the workplace, many employers and policymakers are unaware of the issues (National Academies of Sciences & Medicine, 2016). Much of the currently available research on caregiving and work is outdated, consists of one-off studies that offer limited new knowledge, and single company studies with findings that are difficult for employers to apply. Also, progress towards addressing challenges is impeded by a lack of standardized metrics and methods, and too few longitudinal studies. What limited information is available on CEs is descriptive and general. For example, research rarely analyzes caregiving patterns according to occupational groups, access to employee benefits offerings, type of employer or industry. Evidence pertaining to workplace interventions for caregivers is practically non-existent. Thus, the research often fails to resonate with employers and lacks the nuances necessary for a company to act.

AIMS AND APPROACH

Employers are in a race to attract and retain the best talent. Caregiving represents both a threat and an opportunity. The aim of this white paper is to update the relevant research on caregivers who are currently or recently employed. Unlike prior research, the information presented is intended to help employers and policymakers answer these key questions:

- Why do we need to know about employees who are or will become caregivers and about caregiving?
- · How are the private and public sectors responding to these trends?
- What are the benefits and costs associated with different options? What could be done differently?

This white paper presents information curated from publications in the peer-reviewed academic research literature and grey literature (which is not peer-reviewed). It is not a systematic review. We considered publications to be eligible for inclusion if they addressed the topic of employee caregivers, informal (i.e., non-professional) caregivers and the workplace, and/or policies and practices related to informal caregivers and the workplace. Materials published between 2010 and 2021 were eligible, though this range was expanded to include publications between 2000 and 2010 that were directly on the topic of interest. We also found that publications about employee caregivers and the workplace were sometimes limited to discussing elder care or long-term care policies, and we included these as well.

Family caregiving overlaps with the broad topic of work/family policy. We included publications on that topic when they substantially addressed family caregivers of individuals with illness, disability or issues of aging. For example, we excluded publications primarily addressing parental leave policies. We also limited inclusion of disease-specific topics such as caregiving for patients with cancer or dementia. Finally, we excluded case studies, entirely qualitative studies, and those reporting on a single employer.

This white paper also relied on national survey results:

 National Survey of Caregivers, a survey of caregivers in US households conducted every five years for the American Association of Retired Persons and the National Alliance of Caregiving (AARP/NAC),

Employers are in a race to attract and retain the best talent. Caregiving represents both a threat and an opportunity. The aim of this white paper is to update the relevant research on caregivers who are currently or recently employed.

- Gallup Healthways Well-being Index survey, which obtains a representative sample of the population in US households, including in 2010-2011 employment and caregiving statistics,
- US Bureau of Labor Statistics' American Time Use Survey (ATUS), which addressed eldercare in 2017-2018, and
- 2011 National Survey of Caregivers (NSOC) of Medicare beneficiaries.
- National Survey of Employers (NSE) from the Society of Human Resource Management (SHRM).

The surveys have certain definitional, methodological, and chronological differences that limit their comparability. Those focused primarily on caregiving supply limited information about caregiver employment.

EMPLOYEE CAREGIVING IS A WIDESPREAD PHENOMENON

In 2019, there were roughly **258.4 million adults in the US**, of which **163.2 million were employed** (United States Bureau of Labor Statistics, 2019). Based on the results of four national surveys family caregivers comprise an estimated 18 and 22% of the US labor force.

Studies repeatedly find that the majority of CEs are employed full-time. An estimated **60%** of CEs work at least 40 hours per week, **15%** work 30-39 hours per week and **25%** work fewer than 30 hours per week. The total average number of weekly work hours among CEs is 35.7 (AARP & National Alliance for Caregiving, 2020).

For the average CE, caregiving is similar in hours to having a demanding part-time job in addition to a paying job.

Caregiving roles and responsibilities sometimes last for years, and involvement can be ongoing or intermittent. Nationally, approximately one-third (34%) of CEs had been providing care for less than one year, 24% for one to two years, 19% for three to five years and 24% for more than five years (AARP & National Alliance for Caregiving, 2020).

Information about CE occupations, employers and organizational characteristics is relatively sparse and based primarily on self-report rather than rigorous classification. Surveys find that CEs are represented in all occupational categories, just over half are in hourly positions and a small portion are self-employed.

In one national survey, most CEs (31%) reported that they
worked in professional occupations, between 10 and 15%,
respectively, were either in service or management occupations,
and under 10% worked in any other occupational categories
(Witters, 2011).

Caregiving and Employment

In 2019, an estimated **53.0 million adults 18** years of age or older provided care in the past **12 months of which 61% were employed** and account for an estimated 21.8% of the employed population. (AARP & National Alliance for Caregiving, 2020).

In a 2010-2011 survey of employed adults in US households, an estimated 18% were CEs, employed at least 15 hours per week and providing care for an elderly or disabled family member, relative or friend (Cynkar & Mendes, 2011), equivalent to an estimated 17.1% of US full-time employees (19.1 million individuals), (Witters, 2011).

A 2017-2018 national survey of how Americans spend their time, estimated that 40.4 million people in the US ages 15 and older, 15.5% of the total US population were providing eldercare.

Approximately 63% of these caregivers were also employed, representing 15.5% of the total US employed population. (United States Bureau of Labor Statistics, 2019).

In 2011, a national survey of caregivers of Medicare beneficiaries found that **half of the 17.7 million elder caregivers were employed** (8.7 million Americans) of which more than two-thirds were employed full-time. (*National Academies of Sciences & Medicine, 2016*).

In 2019, **CEs provided an average of 20 caregiving hours per week** while non-working caregivers provided on average just under 29 hours of care per week (AARP & National Alliance for Caregiving, 2020).

CEs who share a home with a care recipient spend more hours on caregiving on average than CEs who live separately. Among CEs, **31% share a home with a care recipient**. Though lower than the 43% rate among non-working caregivers, this rate is not insignificant (*Feinberg et al.*, 2011).

In 2017-2018, the average CE providing eldercare spent approximately **14 to 15 hours per week** on care (*United States Bureau of Labor Statistics, 2019c*).

- More than half (54%) of all CEs are paid on an hourly basis and 39% are salaried, which is similar to all
 US workers. Generally speaking, salaried positions are associated with more generous pay and benefits (AARP
 & National Allliance for Caregiving, 2020)
- Fifteen percent of CEs are self-employed or business owners. Compared to the US population, caregivers have higher rates of self-employment, though the majority work for an external employer (AARP & National Alliance for Caregiving, 2020). It is not known whether caregiving responsibilities lead to more self-employment, or self-employment leads to more caregiving.

EMPLOYED CAREGIVERS ARE DIVERSE

Caregivers are represented across all employee demographic groups. Women, older adults, and racial/ethnic minorities are disproportionately represented among CEs. Table 1 compares the most detailed data available on the demographic characteristics of CEs, which are somewhat dated, to federal employment statistics from the same time period.

Table 1. Labor Force Participation in the US and Percentage of Full and Part-Time Employed Who Are Family Caregivers

Population Group	US Labor Force Participation Rate 2011 (%)1	Percentage of US Labor Force 2010 or 2011 (%) ¹	Percentage of Caregivers Among the Employed 2010-2011 (%) ²
All Americans	58	59	18
Gender ³			
Male	64	53	16
Female	53	47	20
Age ⁴			
18-29	62	23	13
30-44	86	33	15
45-64	68	40	22
65 or Older	16	5	16
Race ^{3,4}			
White/Caucasian	59	81	17
African American/Black	52	12	21
Asian	60	5	14
Ethnicity ³			
Hispanic/Latinx	59	15	20

¹ Employment statistics were obtained from the following sources: US Bureau of Labor Statistics. Table 1. Employment status of the civilian noninstitutional population by age and sex, 2010 annual averages and Labor Force Characteristics by Race and Ethnicity, 2011 August 2012 Report 1036.

² Cynkar and Mendes, 2011.

³ Statistics are for 16 years of age or older.

⁴ US employment statistics for ages 16-17 and additional racial groups were not reported because corresponding caregiver prevalence rates were not available.

NEGATIVE WORK OUTCOMES ARE COMMON AMONG EMPLOYED CAREGIVERS

Research has found that CEs frequently perceive that their work, careers, and productivity have been disrupted by caregiving. They also identify positive aspects of working while being a caregiver, but these have been examined to a considerably lesser extent (Calvano, 2013).

Caregiver research covers a wide range of different employment outcomes including changes in employment status, work hours, earnings and work performance and work productivity. These outcomes are intertwined with economic well-being at the individual, family, employer and national levels.

Self-Reported Work Impacts

In multiple waves of the AARP/NAC survey, CEs are asked to report on the presence or absence of certain work impacts. The majority of CEs (61%) in the 2019 cohort, as in prior cohorts, experience caregiving as disruptive to employment. Because of caregiving, more than half of the CEs (53%) had to start work late or leave work early, 15% reduced their work hours and 14% took a leave of absence. A group of 8% received a warning about work performance or attendance (AARP & National Alliance for Caregiving, 2020).

The Gallup Healthways survey of employed adults found that **one-fourth of the**CEs felt that caregiving was preventing them from increasing their work

hours (Witters, 2011). The same survey also found that in the past year, more than
one-third of the CEs (36%) were absent between one and five workdays and 30%
six or more days. CEs missed work an average 6.6 days in one year due to caregiving
(Witters, 2011).

Job turnover is another important work impact. In a recent survey of CEs (Fuller & Raman, 2019), almost one-third of survey respondents reported that they had voluntarily left a job at some point during their careers because of their caregiving responsibilities. The main reasons given for leaving were: an inability to find affordable paid help (53%), an inability to find high quality help (44%) and difficulty meeting work demands due to increased caregiving responsibilities (40%). Also, perhaps foreshadowing future turnover, 80% of CEs felt that their caregiving had affected their productivity mostly by preventing them from performing at their highest level of capability (Fuller & Raman, 2019). This implies that a large number of CEs regard their performance as sub-optimal compared to what they could achieve but not substandard relative to what others achieve.

Difficulty functioning effectively at work is another important work outcome and is related to work productivity. Functional outcomes are sometimes bucketed into effects known as "presenteeism" (deficits in at-work functioning) and absenteeism (time spent not functioning at work); (Lerner et al., 2020). Functional outcomes in work are the result of the interaction between the worker, their job, the physical and psychosocial work environment, and organizational culture. Table 2 reports on functional outcomes and work productivity loss in a large national sample of CEs employed 10 hours per week or more.

CEs had difficulty functioning at work approximately **40%** of the time in the prior month. Difficulties affected CE performance of time management at work, physical tasks, mental and

Because of their caregiving responsibilities:

53%

had to start work late or leave work early

15% reduced their work hours, and

14%

took a leave of absence

TABLE 2. Unadjusted Indirect and Direct Costs of Caregiving (Source: Lerner, et al. 2020)

Indirect Costs	Missing	Employed Caregiver N=1,070
Indirect Costs		
Work Limitations Due To Caregiving, At-Work Productivity Loss (Presenteeism)		
Time Management, Mean (SD)	97	43.8 (19.7)
Physical Tasks, Mean (SD)	115	38.1 (21.9)
Mental-Interpersonal Tasks, Mean (Sd)	114	38.1 (15.6)
Output Tasks, Mean (SD)	133	39.4 (18.3)
Percentage Productivity Lost Due To Presenteeism, Mean (SD)	171	10.7 (4.1)
Annualized Cost, Mean (SD)	75	5,280.7 (2,090.6)
Absence Days Missed Per Month, Mean (SD)	119	3.2 (3.7)
Percentage Productivity Lost Due To Absenteeism Mean (SD)	120	2.2 (3.0)
Annualized Cost, Mean (SD)	0	1,123.0 (1,398.7)
Direct Costs to Caregivers		
Imputed Unpaid Caregiving Hours (Mean, SD)	0	14.6 (10.6)
Annualized imputed cost of unpaid caregiving hours, mean (SD)	0	18,952.7 (13,732.3)
Total direct out-of-pocket costs, mean (SD)*	0	20,234.9 (14,481.8)

^{*} All costs are annualized and based on the United States Bureau of Labor Statistics estimated annual average hourly wage of \$25 per hour for 2018. Indirect costs reflect costs due to lost productivity from absenteeism and presenteeism measured with the Caregiver Work Limitations Questionnaire. Direct caregiving hours costs reflect costs accrued by the caregivers if they were paid for their unpaid caregiving hours. The \$25 per hour rate was used to estimate costs. Total direct out-of-pocket costs reflect non-medical expenses such as related to maintaining the household for care recipients.

interpersonal tasks and those related to output (work quality, quantity and timeliness; Table 2). As a result of this reduced performance, the estimated average productivity loss due to presenteeism per CE was almost 11% and the average annualized at-work productivity cost per CE was \$5,281, which assumed conservatively an hourly pay rate of \$25. CEs also missed an average of 3.2 workdays in the prior month, for an estimated average productivity loss of 2.2%. The average annualized cost for absenteeism was \$1,123 per CE. While productivity costs are generally borne by the employer, CEs are also likely to feel the impact on compensation and other rewards.

Table 2 also reports on the direct costs of caregiving to the CE. It includes the estimated cost to CEs for their unpaid caregiving time and their out-of-pocket costs accrued from purchasing household goods and services and other resources for the care recipient. Payments did not include medical care, durable medical equipment, prescriptions and insurance premiums. In this study, unpaid CE care in the prior year was valued at approximately \$19,000 and CEs paid an average of just over \$20,000 out-of-pocket in the prior year.

In addition to the outcomes already discussed, emerging research indicates that CEs frequently perceive that they are at risk of bias and discrimination and unwanted employment consequences.

Employers as well as CEs may not be aware that multiple regulations already are in place that offer CEs some protections (United States Equal Employment Opportunity Commission, 2009). A recent study found that the volume of family responsibility discrimination (FRD) litigation, which encompasses claims related to caregiving, had increased dramatically in the past 10 years compared to the prior decade; a trend that shows no signs of abating (Calvert, 2016). Based on this detailed review of more than 4,000 FRD cases, the authors found that most were complaints related to pregnancy or maternity leave, and the rest were about caregiving: 11% involved elder care, 9% involved care for sick children, 6% for care of a sick spouse and 5% for care of a person with a disability (Calvert, 2016).

Economic Analyses of Work Impacts

While there is a high degree of consistency in self-reported work impacts, economic studies, which focus on outcomes such as employment status, weekly work hours and return to work after a period of unemployment have offered more mixed findings. Some have found support for the harmful effects of caregiving on labor force participation; others have not. In fact, several recent studies have not found strong associations between caregiving and labor force participation. Specifically, a study of parental and spousal caregiving using several waves of Health and Retirement Study data (for adults 51 or older) concluded that caregiving has a small effect on employment status, wages or hours, and that the likelihood of working is somewhat decreased by caregiving for women but not for men (Butrica & Karamcheva, 2018). A separate systematic review of the evidence reached similar conclusions on employment but found a threshold effect of caregiving hours: a relatively high number of care hours was associated with fewer work hours (Bauer & Sousa-Poza, 2015).

Researchers generally agree that labor force participation is influenced by many variables, which have not been sufficiently studied (Fuller & Raman, 2019); (Beauregard & Henry, 2009), including the characteristics of individuals, their caregiving role and requirements, their jobs and work organizations and their communities (e.g., availability of health care and supportive services).

Despite some open questions, and considering the full range of research on caregiving and employment, the main conclusion is that employment repercussions are common occurrences for employed family caregivers.

INTERVENTIONS ARE NOT FIT FOR PURPOSE

This section summarizes research regarding the current status of services and resources, policies and practices that potentially prevent or reduce work-related repercussions, highlighting approaches that are relevant to the workplace. Most of the existing research was completed before the COVID-19 pandemic, which has introduced significant changes in how we work.

Studies provide information about the prevalence of some of these approaches, but gaps remain on issues such as the degree to which these approaches are aligned with CE preferences and needs, are accessible and available to certain groups of CEs, and their

Most caregiving complaints in family responsibility discrimination litigation were related to pregnancy or maternity leave, and the rest were about caregiving:

11%

involved elder care

9%

involved care for sick children

6%

for care of a sick spouse

5%

for care of a person with a disability

outcomes at the CE and organizational levels. Access and availability are key concerns because in the US employee benefits are highly variable by size of the employer, industry sector and employee group, with part-time, hourly and low-wage workers having the least access to certain benefits.

Employee Leave

Employee leave policies are considered a cornerstone of a caregiver friendly workplace (Feinberg, 2013). Caregivers need to be able to take time off from work and that need could take the form of day or part of a workday or an episode consisting of several days or weeks, and this need could begin and end within a circumscribed time period or be intermittent, planned or unplanned. These variable and often unpredictable patterns of caregiving make it somewhat distinct from other family leave needs such as those involved in the birth or adoption of a child or bereavement. Most US companies do not have leave policies that can accommodate the range of needs for caregiving leave.

US employers with 50 or more employees are covered under the rules of the Family and Medical Leave Act of 2013, which allows workers employed for at least 12 months to take job-protected unpaid leaves of absence for 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. In 2012, approximately 44% of the private sector labor force was not eligible for FMLA coverage (Jorgensen & Appelbaum, 2014). In addition to the gaps in who is covered, there is a high degree of consensus that the FMLA simply does not go far enough to address caregivers' needs for leave. Its maximum duration of leave, restrictions on who the leave is being taken for, and the loss of income involved make it a poor fit for some caregivers, particularly among workers who can't afford to not work, are problematic. Some states and employers now offer expanded coverage, which has helped to address some of these shortcomings and fill in gaps (Mudrazija & Johnson, 2020).

As of 2019, eight states and the District of Columbia have experimented with implementing paid leave policies (National Partnership for Woman & Families, 2019). These typically are funded through employer contributions and provide wage replacement for eligible employees. Evidence from program evaluations in California, New Jersey, Massachusetts and Rhode Island suggest that employees who took advantage of the benefit were satisfied and employers did not find the program to be burdensome. Utilization barriers such as a lack of awareness of the program and employee concern about job repercussions remain challenges.

Policy analysts have also advocated for solutions that address income loss during periods of extended leave. One such proposal would relax state unemployment insurance requirements (e.g., providing documentation of active job searching), which could enable caregivers to receive income while temporarily off the job (Ben-Ishai et al., 2015). The Social Security Caregiver Credit Act has been introduced in various forms since approximately 2013 and would give caregivers an earnings history for the time they are away from work providing dependent care for a limited number of years (Gonzales et al., 2015).

In private industry, approximately **75**% of full-time employees and **16**% of part-time employees are eligible for some type of paid leave, though the prevalence of leave policies tailored for caregivers has not been tracked and presumably is small (Van Giezen, 2013). Studies suggest that even when available, certain barriers have prevented CEs from taking advantage of their

Caregivers need to be able to take time off from work and that need could take the form of day or part of a workday or an episode consisting of several days or weeks, and this need could begin and end within a circumscribed time period or be intermittent, planned or unplanned.

paid leave benefits. One survey of CEs from many different companies reported that paid leave was the most frequently used caregiver benefit but that only 55% of those eligible had taken advantage of it (Fuller & Raman, 2019). The National Survey of Employers (NSE), a large panel survey of companies with more than 50 employees in the private and public sectors, conducted by the Society of Human Resource Management (SHRM) (Matos et al., 2016), found that the average maximum number of weeks of parental or caregiving leave in 2016 was about the same as in 2012. In at least 90% of the companies, employees were allowed to take job-protected paid days off such as sick or personal days to care for spouses, parents or children. The rate declined substantially when the request was for the care of a more distant relative or domestic partner. A sizeable portion of employers also reported that supervisors acted as gatekeepers to paid leave, and were permitted to ask employees for their reasons for requesting time off. Other employers had "needsblind" leave policies and practices. More than a third (38%) of employers indicated that supervisors evaluated the employee's reasons for the request. Finally, only 25% of employers had made a specific effort to keep employees informed about the benefits available for managing work and family responsibilities.

Flexible Work Arrangements

Flexible or alternative work arrangements are also widely considered a cornerstone of CE policy. Flexible work arrangements are often touted as being a key mechanism for alleviating work-family conflicts and more generally for achieving benefits such as improved hiring, retention and work productivity. Research from a variety of different fields doesn't fully support these assertions. However, all of the research was conducted before the start of the COVID 19 pandemic and it is not known how well these results will generalize to today's workers and companies.

SHRM has studied the availability of several types of flexible work arrangements. Flex time options include giving employees choices in managing their own time including when they work and how they use their time at work, use of part-time or part-year schedules, ability to have time away from work for caregiving, ability to take time off and the like. Flex locations include giving employees the ability to choose where they work. Flex careers include ability to make decisions about exiting or re-entering the workforce. A culture of flexibility refers to awareness in the workplace, particularly among supervisors, about flex policies.

When employers were asked about the availability of these options for caregivers in 2016, the most commonly used options were those allowing employees to take time off during the workday without losing pay (47% of companies). Least common in this pre-pandemic period were work from home options, which were allowed in under 10% of companies. Jobs with flexible schedules or work locations tended to be available only to CEs in salaried positions.

Another survey of work arrangements in the US economy over the past 20 years found that they have been relatively unchanged (Mas & Pallais, 2020). Most jobs (pre-pandemic) were still traditional in how they were structured. A key finding was that jobs with schedule or location flexibility tended to be less family-friendly (e.g., not sufficiently reducing conflict between work and family life) and, therefore, women were less likely to choose these jobs and more likely to work part-time. Flexible schedules were associated with higher job demands.

One survey of CEs from many different companies reported that paid leave was the most frequently used caregiver benefit but only

55%

of those eligible had taken advantage of it.

While flexibility in work schedules and location were assumed to contribute to work-life balance, this study did not find that workers in more flexible jobs had less stress or fewer family life interruptions than women in traditionally structured jobs.

Cross-Over Benefits

A variety of employee benefits, which were not specifically designed to reduce the burden of caregiver, have the potential to do so. Both employees and employers may not be taking full advantage of these. One is the dependent care account, which sets aside a specified amount of job earnings each year as pre-tax dollars to cover expenses such as childcare. Employees may not be fully aware of the costs involved in caregiving and the value of setting aside funds. Employer-sponsored long-term care insurance is another type of employer-sponsored benefit though it is not widely available and employee uptake has been limited due to cost. However, long-term care insurance plans may be another vehicle for caregiver support. For example, plans may be modified to include provisions to pay family members for caregiving time and costs. Employers are also likely to be overlooking the potential value of keeping employees informed of Medicare and Medicaid offerings for their qualified care recipients. Some public insurance benefits such as hospice and respite care, as well as the emerging consumerdirected benefit options that allow care recipients to designate and reimburse a family member as a paid helper, could have a positive impact on CEs (Kaye, 2014). Generally, employers could do more to increase awareness of benefits and how to use them as well as to ensure that the benefits they sponsor include provisions to address care recipient and caregiver needs.

Caregiver-Focused Service Lines

Finally, a variety of innovations are occurring in the private-sector to enhance caregiver supports and resources including new companies in the caregiver market space and new service lines within existing businesses such as health insurers, health care provider organizations and Employee Assistance Programs (EAPs). In the eldercare space, studies find that the majority of US companies offer some form of assistance to employees though not necessarily all employees (Calvano, 2013); (Dembe et al., 2008). The most common forms of assistance include information, education and referral services, while direct financial assistance and care management are less common. Currently, little is known about private-sector services, including their utilization, effectiveness and costs.

NEXT STEPS

This white paper highlights the large number of current and future CEs across all employee and employer subgroups, the documented consequences resulting from attempting to blend caregiving and work, and the limited amount of progress in implementing effective solutions. These provide a powerful rationale for why addressing caregiving is a business imperative and relevant to business leaders. However, there are still gaps in knowledge. We know a great deal more about the human and economic costs of caregiving, but little about the costs and benefits of solutions to reduce the burden on CEs and their employers. To have an impact, the pace of CE-relevant and employer-relevant research will have to increase but there are likely many lessons that already can be learned. Employers have gained a great deal of experience implementing benefits under the work-family practices

Employers could do more to increase awareness of benefits and how to use them as well as to ensure that the benefits they sponsor include provisions to address care recipient and caregiver needs. umbrella and some have already adopted caregiver support initiatives. These experiences could provide an initial basis for best practices. In addition, several actions could be taken quickly and make use of existing infrastructure. These include:

- Adding a caregiving module to ongoing employee surveys or as part of open enrollment that, to the degree possible, use available standardized metrics to enable more data-sharing and comparison;
- Establishing an employee caregiving interest group, representing a diverse range of CEs, to serve as a resource to management and other employees;
- Taking an inventory of existing policies and services that conceivably could
 apply to CEs but are scattered throughout and vetting alignment with known
 caregiver issues, the volume of usage and barriers to their use;
- Engaging leadership in showing support for CEs and reducing stigma;
- Educating employees and the benefits and services they now have and how to use them;
- Educating employees about Medicare and Medicaid coverage for care recipients, hospice and other community-based long term care services that can help lighten the load on CEs;
- **Training managers** on the issues and providing adequate back-up to help them interact effectively with CEs;
- Working with existing health care insurers and third-party claims processing
 companies to evaluate the accuracy of claims and billing and reduce errors that are
 financially and emotionally costly to CEs and their families;
- When preparing requests for proposals (RFPs) and contracts for service vendors such
 as health care insurers and providers, requiring them to include caregiving-friendly
 workplace services and mandating reporting on key performance and outcome metrics
 such as those presented in this report (e.g., utilization of paid leave, decreasing work
 hours, presenteeism and absenteeism);
- Collaborating on efforts to identify gaps in benefits and services and creating guidelines for a standard minimum package; and
- Collaborating on efforts to **develop standardized metrics and benchmarking reports** to facilitate comparison across employers and industries.

Employers and policymakers could also contribute their considerable influence outside of the workplace. Increased advocacy is needed to create a national caregiver database with information obtained from caregivers and employers as well as to support health care and labor sector initiatives that have the potential to help current and future CEs and their families.

Increased advocacy is needed to create a national caregiver database with information obtained from caregivers and employers as well as to support health care and labor sector initiatives that have the potential to help current and future CEs and their families.

REFERENCES CITED

AARP & National Alliance for Caregiving. *Caregiving in the United States* 2020. Washington, DC: AARP. May 2020. https://doi.org/10.26419/ppi.00103.001

Bauer, J. M., & Sousa-Poza, A. (2015). Impacts of Informal Caregiving on Caregiver Employment, Health, and Family. *Journal of Population Ageing*, 8(3), 113-145. https://doi.org/10.1007/s12062-015-9116-0

Beauregard, T. A., & Henry, L. C. (2009). Making the Link Between Work-Life Balance Practices and Organizational Performance. *Human Resource Management Review.*, 19(1), 9-22. https://doi.org/10.1016/j.hrmr.2008.09.001

Ben-Ishai, L., McHugh, R., & Ujvari, K. (2015). Access to unemployment insurance benefits for family caregivers: An analysis of state rules and practices. Washington, DC: AARP Public Policy Institute. https://www.nelp.org/publication/access-unemployment-insurance-benefits-family-caregivers-analysis-state-rules-practices/

Body, D. (2020). The True Cost of Caregiving; Why An Equitable Care System For Children, Adults, And Elders Is Essential To Household Financial Security. The Aspen Institute Financial Security Program. https://www.aspeninstitute.org/wp-content/uploads/2020/05/The-True-Cost-of-Caregiving.pdf

Butrica, B. A., & Karamcheva, N. S. (2018). The impact of informal caregiving on older adults' labor supply and economic resources. Proceedings. Annual Conference on Taxation and Minutes of the Annual Meeting of the National Tax Association,

Calvano, L. (2013). Tug of War: Caring for Our Elders While Remaining Productive at Work. *Academy of Management Perspectives*, 27(3), 204-218. https://doi.org/10.5465/amp.2012.0095

Calvert, C. (2016). Caregivers in the workplace: Family responsibilities discrimination litigation update 2016. Center for WorkLife Law at UC-Hastings College of Law. https://worklifelaw.org/publications/Caregivers-in-the-Workplace-FRD-update-2016.pdf

Cynkar, P., & Mendes, E. (2011). *More Than One In Six American Workers Also Act As Caregivers*. Gallup. https://news.gallup.com/poll/148640/one-six-american-workers-act-caregivers.aspx

Dembe, A., Dugan, E., Mutschler, P., & Piktialis, D. (2008). Employer perceptions of elder care assistance programs. *Journal of Workplace Behavioral Health*, 23(4), 359-379. https://doi.org/10.1080/15555240802540012

Ding, R., Dardas, A., Wang, L., & Williams, A. (2020). Evaluation of a Caregiver-Friendly Workplace Program Intervention on the Health of Full-Time Caregiver Employees: A Time Series Analysis of Intervention Effects. *Journal of Occupational and Environmental Medicine*, 62(10), e548-e558. https://doi.org/10.1097/JOM.00000000000001980

Feinberg, L. (2013). Keeping up with the times: Supporting family caregivers with workplace leave policies. Washington, DC: AARP. https://www.aarp.org/home-family/caregiving/info-06-2013/supporting-family-caregivers-with-workplace-leave-policies-AARP-ppi-ltc.html

Feinberg, L., Reinhard, S. C., Houser, A., & Choula, R. (2011). Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving. Washington, DC: AARP Public Policy Institute. https://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf

Fuller, J. B., & Raman, M. (2019). The Caring Company. *Harvard Business School*. https://www.hbs.edu/managing-the-future-of-work/
Documents/The_Caring_Company.pdf

Gonzales, E., Matz-Costa, C., & Morrow-Howell, N. (2015). Increasing opportunities for the productive engagement of older adults: a response to population aging. The Gerontologist, 55(2), 252-261. https://doi.org/10.1093/geront/gnu176.

Ireson, R., Sethi, B., & Williams, A. (2018). Availability of caregiver-friendly workplace policies (CFWPs): an international scoping review. Health and Social Care in the Community, 26(1), e1-e14. https://doi.org/10.1111/hsc.12347

Jorgensen, H., & Appelbaum, E. (2014). Expanding Federal Family and Medical Leave Coverage. Washington, DC: Center for Economic and Policy Research. https://cepr.net/documents/fmla-eligibility-2014-01.pdf

Kaye, H. S. (2014). Toward a model long-term services and supports system: state policy elements. *The Gerontologist*, *54*(5), 754-761. https://doi.org/10.1093/geront/gnu013

Keating, N. C., Lero, D. S., Fast, J., Lucas, S. J., & Eales, J. (2013). *A Framework and Literature Review on the Economic Cost of Care.*Centre for Families, Work & Well-Being, University of Guelph. https://acrre.ualberta.ca/acrre/wp-content/uploads/sites/49/2018/04/EconomicCostsofCareFrameworkLitReview2013.pdf

Kelly, E. L., Kossek, E. E., Hammer, L. B., Durham, M., Bray, J., Chermack, K., Murphy, L. A., & Kaskubar, D. (2008). Getting There from Here: Research on the Effects of Work-Family Initiatives on Work-Family Conflict and Business Outcomes. *The Academy of Management annals*, 2, 305-349. https://doi.org/10.1080/19416520802211610

Lerner, D., Lavelle, T. A., Adler, D., Chow, W., Chang, H., Godar, S. C., & Rogers, W. H. (2020). A Population-Based Survey of the Workplace Costs for Caregivers of Persons With Treatment-Resistant Depression Compared With Other Health Conditions. *Journal of Occupational and Environmental Medicine*, 62(9), 746-756. https://doi.org/10.1097/JOM.0000000000000000057

Lilly, M. B., Laporte, A., & Coyte, P. C. (2007). Labor market work and home care's unpaid caregivers: a systematic review of labor force participation rates, predictors of labor market withdrawal, and hours of work. *The Milbank Quarterly, 85*(4), 641-690. https://doi.org/https://doi.org/https://doi.org/https://doi.org/10.1111/j.1468-0009.2007.00504.x

Mas, A., & Pallais, A. (2020). Alternative Work Arrangements. *Annual Review of Economics*, 12(1), 631-658. https://doi.org/10.1146/annurev-economics-022020-032512

Matos, K., Galinsky, E., & Bond, J. (2016). National Study of Employers. *Society for Human Resource Management*. https://www.shrm.org/hr-today/trends-and-forecasting/research-and-surveys/Documents/National%20Study%20of%20Employers.pdf

Mudrazija, S., & Johnson, R. (2020). Economic Impacts of Programs to Support Caregivers.

National Academies of Sciences, Engineering, & Medicine. (2016). Families Caring for an Aging America. Washington, DC: The National Academies Press. https://doi.org/doi:10.17226/23606

National Partnership for Woman & Families. (2019). *Paid Leave Works: Evidence from State Programs*. https://www.nationalpartnership.org/our-work/resources/economic-justice/paid-leave/paid-leave-works-evidence-from-state-programs.pdf

Reinhard, S. C., Levine, C., & Samis, S. (2014). Family caregivers providing complex chronic care to their spouses. *Washington, DC: AARP Public Policy Institute*. https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2014/family-caregivers-providing-complex-chronic-care-spouses-AARP-ppi-health.pdf

Silver, B. E., Mederer, H., & Djurdjevic, E. (2016). Launching the Rhode Island Temporary Caregiver Insurance Program (TCI): Employee Experiences One Year Later. *United States Department of Labor Women's Bureau*, 5-67. https://web.uri.edu/ssirep/files/RI-Paid-Leave-Final-Report-April-2016.pdf

United States Bureau of Labor Statistics. (2019a). *Employment Situation News Release. USDL-19-0360*. United States Department of Labor. https://www.bls.gov/news.release/archives/empsit_03082019.htm

 $\label{lem:continuous} United States Bureau of Labor Statistics. (2019b). \textit{Labor Force Characteristics By Race and Ethnicity, 2018}. United States Department of Labor. \\ \underline{\text{https://www.bls.gov/opub/reports/race-and-ethnicity/2018/pdf/home.pdf}}$

United States Bureau of Labor Statistics. (2019c). Unpaid Eldercare In The United States — 2017-2018 Data From The American Time Use Survey; USDL-19-2051. United States Department of Labor. https://www.bls.gov/news.release/pdf/elcare.pdf

United States Bureau of Labor Statistics. (2020). Labor Force Share, by Age Group, 1998, 2008, 2018, and Projected 2028. United States Department of Labor. https://www.bls.gov/emp/graphics/2019/labor-force-share-by-age-group.htm

United States Department of Labor Statistics. (2021). Labor force statistics from the Current Population Survey. United States Department of Labor. https://www.bls.gov/cps/cpsaat11b.htm

United States Equal Employment Opportunity Commission. (2009). Employer Best Practices for Workers with Caregiving Responsibilities. Title VII, 29 CFR Part 1604. United States Equal Employment Opportunity Commission. https://www.eeoc.gov/laws/guidance/employer-best-practices-workers-caregiving-responsibilities

Van Giezen, R. W. (2013). Paid Leave In Private Industry Over The Past 20 Years. *Journal of Health Economics*. https://doi.org/10.1016/j.jhealeco.2012.10.006

Van Houtven, C. H., Coe, N. B., & Skira, M. M. (2013). The effect of informal care on work and wages. *Journal of Health Economics.*, 32(1), 240-252. https://doi.org/10.1016/j.jhealeco.2012.10.006

Witters, D. (2011). Caregiving costs US economy \$25.2 billion in lost productivity. Gallup Well-Being. https://news.gallup.com/poll/148670/caregiving-costs-economy-billion-lost-productivity.aspx

Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Internal Medicine*, 176(3), 372-379. https://doi.org/10.1001/jamainternmed.2015.7664

A note from the author

I would like to acknowledge the research contributions of Naomi Bridger BS and Karen Kavanaugh, Chief, Strategic Initiatives, Rosalynn Carter Institute for Caregivers, whose assistance made this white paper possible.

This white paper is dedicated to my mother Evelyn Lerner who, as one her final gifts, gave me both the honor of being one of her caregivers and a deeper understanding of the meaning behind the facts and figures.

A note from RCI

RCI would like to thank our donors and funders for supporting this effort, with special recognition for the Ralph C. Wilson Jr. Foundation and Cambia Health Foundation.

ROSALYNN FOR
CARTER CAREGIVERS
INSTITUTE

Contact Us

Email: info@rosalynncarter.org

Phone: 229-928-1234

PO Box 647

Americus, GA 31709

Follow Us







