

## Policies and Interventions to Support Working Caregivers

### Executive Summary

The current demographic and health shifts toward an older U.S. population with multiple chronic conditions, coupled with the trending wish to age in place, have created a growing population of older adults requiring care as well as a corresponding population of individuals caring for older adult family members. These caregivers are subject to health, financial, and quality of life impacts resulting from their caregiving role and responsibilities. Many of these caregivers work outside the home in paid employment, and this carries implications for the caregivers, their care recipients, and their employers. Because of the importance of working caregivers' personal health and quality of life, addressing this group's needs is of utmost concern.

Support for working caregivers may fall into one of three categories: (1) federal- and state-level policies and legislation, (2) employer-sponsored policies and benefits, or (3) workplace interventions. In addition to the Family and Medical Leave Act (FMLA) of 1993, the federal act mandating access to job-secured unpaid leave for illness or caregiving, states are enacting supplemental legislation. States may pass family medical leave laws to increase access to unpaid leave, paid family medical leave laws to provide salary replacement for workers taking unpaid leave, or paid time off laws to require that employers make paid time off available. Additionally, employers may opt to provide benefits to caregiving employees, such as education or supportive services, or to implement caregiver-supportive personnel policies. Lastly, employers may choose to allow or offer access to direct interventions through the workplace.

Improving the health and quality of life of working caregivers of older adults is a public health issue and an opportunity to achieve health equity. Policymakers, employers, and researchers are all in a position to advance the state of the issue by developing and implementing new solutions and identifying best practices. As state health agencies (SHAs) [champion the triple aim of health equity](#), they have an opportunity to consider and support caregiver health in policies and partnerships.

### Introduction

As the U.S. population ages, the unprecedented proportion of older adults among the population is expected to rise to 20 percent by 2030.<sup>1</sup> With the escalation in the presence of multiple chronic conditions among all age groups, and with aging as the most recognized risk factor for developing dementia and Alzheimer's disease, this demographic shift has resulted in a surge in the proportion of the population requiring care or assistance for daily living.<sup>2,3</sup> Alongside this surge, a preference for aging in place—a desire to remain in one's current community as long as possible—has grown among those requiring care.<sup>4</sup> These simultaneous trends have led to an increase in caregiving responsibilities placed on the family members of older adults: The National Alliance for Caregiving (NAC) recently estimated that 34.2 million American adults have served as an unpaid caregiver to someone age 50 or older in the last year.<sup>5</sup>

This growing group encompasses numerous identities, but the typical caregiver of an adult age 50 or older is female and approximately 50 years old.<sup>6</sup> However, the number of male caregivers is also growing.<sup>7</sup> Twenty-four percent of caregivers of older adults are caring for someone with Alzheimer's disease or dementia, whether or not it is the main condition affecting the care recipient. The average time per week spent providing care is 24.1 hours, and caregivers of older adults assist with numerous activities. They may help with activities of daily living (e.g., getting in and out of bed) as well as instrumental activities of

daily living (e.g., transportation, shopping, or chores). Caregivers of older adults suffering from multiple conditions find themselves coordinating care and monitoring their loved one's condition and some even provide assistance with medical or nursing tasks.<sup>8</sup>

Caregivers may experience financial, health, and quality of life issues as a result of their family responsibilities. Housing or caring for an aging family member can place a significant financial strain on an individual.<sup>9,10</sup> In a recent study conducted for NAC and the AARP Public Policy Institute, 17 percent of caregivers of older adults reported experiencing a high level of financial strain.<sup>Error! Bookmark not defined.</sup> Additionally, 20 percent reported that their own health had declined due to their caregiving role. Documented health effects of caregiving include physical ailments such as high blood pressure and physical pain as well as mental health consequences like high levels of emotional stress and increased rates of depression.<sup>11,12,13</sup> Family caregivers of individuals with dementia are even more likely to experience anxiety, depression, and diminished quality of life.<sup>14,15</sup> The National Academies of Sciences, Engineering, and Medicine now deem providing care for persons with chronic conditions or disabilities a public health concern.<sup>16</sup>

Many family caregivers of older adults work outside the home in paid employment: 60 percent of caregivers of older adults sampled by NAC were employed at some point in the last year. In turn, 60 percent of that group reported that caregiving has affected their work.<sup>17</sup> The impacts of caregiving may disproportionately affect the overall quality of life of caregivers employed outside the home by negatively influencing work-life balance and job satisfaction.<sup>18</sup> The most frequently noted impacts of caregiving on work include going into work late or leaving work early, taking time off or a leave of absence, receiving a warning related to performance or attendance, or stopping working altogether, including early retirement.<sup>19</sup> For caregivers experiencing these impacts or otherwise changing their career paths due to caregiving responsibilities, a reduction in lifetime earnings and resulting retirement benefits is likely to follow.<sup>20</sup>

The challenges facing individual caregivers also have a broader societal impact. These burdens transfer to the public and employers through lost productivity and turnover: NAC estimates that the cost to employers due to lost productivity of employee caregivers is as high as \$34 billion.<sup>21,22</sup> Employers face diminished work performance by caregiver employees, absenteeism and lost work time, and, in cases where employees must leave work to undertake full-time caregiving, costs associated with recruitment and training of a replacement.<sup>23,24</sup> Additionally, the ramifications of caregiving reach beyond the individual through the noted healthcare costs incurred by those experiencing caregiving-related health issues.<sup>25</sup>

The specific needs of caregivers are varied; however, 84 percent of caregivers of older adults report a need for information on caregiving topics, including information about keeping their family member safe at home, making end-of-life decisions, and, notably, managing their own stress. For those performing medical tasks, additional informational needs include managing their care recipient's challenging behaviors and incontinence. Caregivers of individuals with Alzheimer's disease or dementia are more likely than others to identify a need for information on managing their own stress as well as challenging behaviors.<sup>26</sup> In addition to these informational needs, employed caregivers, in particular, also tend to identify a need for flexibility in work schedules, information about services, and support from coworkers and supervisors.<sup>27</sup> Because of the unique needs of this growing population and the consequences to

employers, the workplace is an important venue through which to support employed caregivers and reduce the significant impacts of their personal responsibilities.

## Approaches

Targeted support for caregivers through the workplace may fall into one of three categories: (1) federal- and state-level policies and legislation, (2) employer-sponsored policies and benefits, or (3) workplace interventions. Effective programs and policies are ones that have had a demonstrated positive impact on caregiver employees' health or quality of life indicators. There is a limited body of rigorous evidence supporting specific policies, benefits, and interventions, but it is valuable to consider the options within each category and to highlight findings from completed evaluations.<sup>28</sup>

### *Federal- and state-level policies and legislation*

The most influential federal policy affecting working caregivers is FMLA, which provides job protections for qualifying employees that take unpaid leave for caregiving related to an employee's own serious health condition or that of a parent, spouse, or child.<sup>29</sup> FMLA carries various restrictions, and some states have supplemented the minimum coverage provided by FMLA and instituted complementary policies.

To expand upon FMLA, states have passed legislation targeted to employed family caregivers and implemented various policies to benefit this group. Such policies are often included in larger bills addressing medical, family, or disability benefits. Table 1 catalogs the broad types of state-legislated policies allowing employees access to paid or unpaid leave to care for a family member. Costs associated with these benefits may fall on employers directly or a mechanism

<b>Table 1. State Policies Affecting Working Caregivers</b>
<b>Family medical leave laws:</b> States enact these laws as a supplement to FMLA in order increase access to unpaid leave for caregiving.
<b>Paid family medical leave laws</b> mandate that states will provide some level of salary replacement to employees taking family medical leave through FMLA or another policy. The amount of money available to employees utilizing this benefit is subject to restrictions.
<b>Paid time off</b> , when mandated by a state, requires that employers make paid time off available to employees for personal illness or caregiving. The number of allowable hours is subject to restrictions.

such as a payroll tax may provide financing. Typically, paid family medical leave is structured like temporary disability insurance and administered through the state's department of labor. One state has also made this insurance benefit available to the unemployed. Additionally, a handful of states have mandated that an employee may use any sick leave for caregiving. However, state laws may not cover all residents. Many state laws exclude employers by size<sup>i</sup> or category,<sup>ii</sup> require employees to work a certain number of months or hours to be eligible for family leave benefits, and define the family members for whom a caregiver may use the leave. Paid time off policies can also exclude certain employees and often contain restrictions in the total amount of leave that can be accrued and carried over from year to year. This can have the effect of limiting the applicability of these options to certain caregivers.

<sup>i</sup> In Maine, for example, employers with 15 or more employees must offer unpaid family leave, while the majority of states require this only of employers with 50 or more employees.

<sup>ii</sup> For instance, parochial, primary, and secondary schools in Connecticut are excluded from the mandate to offer family medical leave.

Robust evidence on the impacts of various types of state leave legislation on caregivers and their families is limited. According to the AARP Public Policy Institute, the best protection for working caregivers is having ample access to paid leave to care for their adult family member.<sup>30</sup> It is also useful to acknowledge caregiver preferences when considering the most beneficial policy options. When presented with three financial policy or program options, caregivers of older adults in a study conducted for NAC and the AARP Public Policy Institute said that receiving payment for some of their hours spent caregiving and receiving an income tax credit would be most useful. Additionally, job security is of particular concern: 67 percent of the caregivers of older adults in that study supported a policy banning workplace discrimination against this group.<sup>31</sup>

### *Employer-sponsored policies and benefits*

Employers have an opportunity to support the growing population of working caregivers by making an impact on employees' work-life balance to the benefit of employers, caregivers, and care recipients. Employer-sponsored policies and benefits fall into two general categories: (1) caregiver information and support and (2) personnel policies.<sup>32</sup> Through employee assistance programs, many employers offer supportive services for caregivers including counseling and support groups, coordination, referrals to services, wellness programs, eldercare tools, informational resources, and educational seminars.<sup>33,34</sup> Caregiver information and support benefits also take the form of web-based informational and support services; financial benefits, such as discounts on emergency home care; care coordination services; and eldercare services such as adult day care, respite care, or home health provision.<sup>35,36,37,38</sup> Personnel policies might allow for any number of supplemental paid leave models or offer flexible scheduling options to employees.<sup>39,40</sup> Currently, about half of working caregivers of older adults have access to flexible work hours, and about a quarter are offered telecommuting opportunities and the services of employee assistance programs. Employer-sponsored benefits are most available to those working full-time.<sup>41</sup>

Employee caregivers have benefited from employer-sponsored eldercare services as well as workplace leave policies and flexible schedules. In a nationwide survey of 447 caregivers utilizing employer-provided eldercare published in the *International Journal of Workplace Health Management*, respondents indicated that these services helped to maintain their productivity (74.0%), avoid absenteeism (65.5%), maintain employment (58.0%), and experience a good family life at home (72.1%). Although a majority of respondents (55.2%) felt that these services did not help to decrease the financial burden associated with caregiving, they were still satisfied that the services offered were somewhat or very useful in helping to find and arrange care (84.8%) and to ensure good quality care (64%).<sup>42</sup> Regarding personnel policies, employers in one evaluation reported that paid sick leave results in benefits for employees and employers, including improved productivity (89%) and decreased turnover (96%).<sup>43</sup> NAC also asked over 1,000 family caregivers of older adults whether they have found or would find various services and policies helpful. Although this study did not directly evaluate employee benefits, respondents reported that respite services would serve an important role (35%), and this was especially true for those caring for someone with Alzheimer's disease or dementia—47 percent of this group considered the availability of respite services to be helpful.<sup>44</sup>

### *Workplace interventions*

Increasingly, employers are offering direct interventions for caregivers, and a sample of these have been rigorously evaluated. Workplace interventions encompass targeted programs or supportive services geared directly towards employees caring for an adult family member. The most commonly documented

type of workplace intervention is educational; these programs may occur in-person or via the web.<sup>45,46</sup> Other interventions focus on social support through virtual media. In one example, 299 participants in a web-based support program experienced “significant improvements in depression ( $p=.009$ ), anxiety ( $p=.03$ ), level and frequency of stress ( $p<.001$ ), caregiver strain ( $p=.028$ ), self-efficacy ( $p=.016$ ), and intention to seek help ( $p=.002$ ), as well as perceptions of positive aspects of caregiving ( $p=.021$ ).”<sup>47</sup> Additionally, one small assessment ( $n=35$ ) found a series of on-site educational sessions to be evaluated highly on the measures of usefulness, quality, and value by employee caregiver attendees ( $M\geq 4.45$  on a 1-5 scale). Importantly, this program determined the session content through an employee needs assessment to identify the most salient topics for caregivers in that workplace.<sup>48</sup>

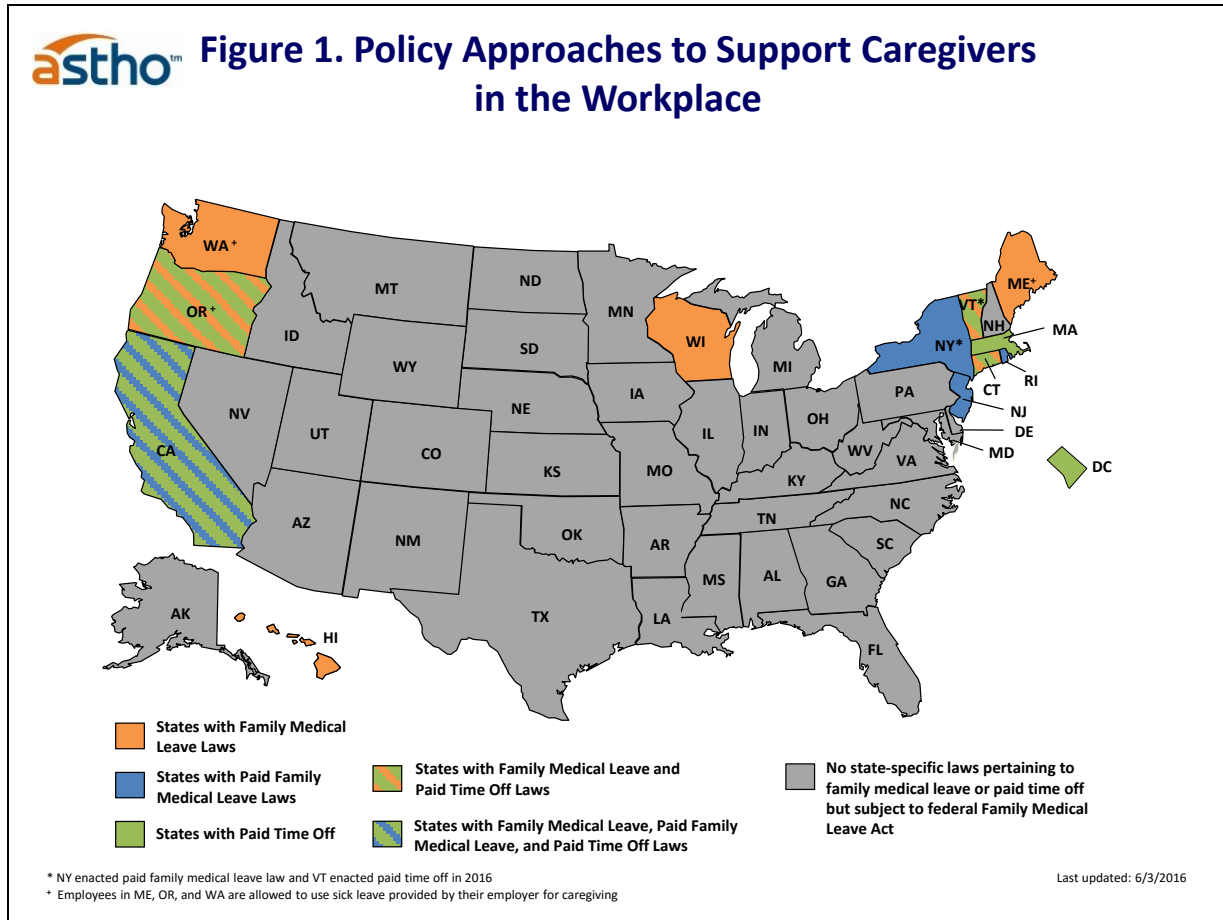
## **Proposed Responses**

The adverse effects of caring for an aging family member on one’s health and quality of life warrant the attention of the public health community, and it is possible to access a large segment of the population of caregivers through the workplace. The current evidence base outlines potential responses to this issue on the part of policymakers, employers, and researchers.

### *For Policymakers*

In the absence of a federal initiative to expand upon or add to FMLA, state-level policies to complement FMLA may meet the needs of working caregivers. By attending to the needs of working caregivers when drafting leave legislation, policymakers can provide immense support to caregivers of older adults, particularly in the short term. In addition to enacting caregiver-supportive leave policies and mandated benefits, state policymakers also have an opportunity to reduce the restrictions on the availability of leave for caregiving by expanding the number of employers who must offer unpaid leave, expanding the definition of care recipients and of applicable conditions, expanding eligibility guidelines for employees, or expanding the maximum duration of leave or the timeframe over which it may be taken. These additions to leave policies have a high impact on the caregiver population and their families.

Currently, for employees that need time off of work to care for an older adult family member in the majority of states, the only protections available to them are through FMLA and any leave-related benefits offered by their employers. However, state legislatures have been increasingly involved in proposing and considering leave laws. Figure 1 illustrates the current situation in the United States regarding state leave laws.



As a significant part of the public health infrastructure, SHAs can play a potentially large role in addressing the health and quality of life of working caregivers by securing and implementing supportive benefits and policies for this population. SHAs can serve in a variety of roles to this end, including acting as developers and proponents of leave legislation, consulting with businesses to best support employee caregivers, and partnering with academic institutions to evaluate programs and policies in order to increase the evidence base. Additionally, SHAs’ expertise in public health communications strategies could serve a huge role in ensuring that working caregivers are fully aware of the benefits available to them under the law. In many cases, state civil service laws provide employees with protections beyond the mandated minimums. As large-scale employers, state governments and SHAs can model best practices in providing caregiver-supportive benefits and implementing new or successful programs.

### *For Employers*

Employers stand to benefit from providing services, implementing programs, enforcing policies, and otherwise supporting their caregiver employees. Current evidence indicates that providing eldercare services and care coordination, making educational programs available, and offering supportive leave policies and flexible schedules are the most effective methods of improving health and well-being for working caregivers. Workplace support programs for caregivers may take many forms, but effective, comprehensive programs include a consistent set of dimensions. Caregivers benefit from flexibility in

hours and location, information about and linkages to community resources, assistance with decisions regarding services, referrals to elder law professionals, care management services, and privacy in accessing services.<sup>49</sup> Additionally, numerous sources have highlighted the importance of awareness: Any programs implemented should involve a component that makes employees aware of available benefits and services and of relevant policies.<sup>50,51</sup> Most importantly, employer-sponsored programs should be dynamic and adapt to the changing needs of their caregiver employees.<sup>52</sup>

### *For Researchers*

Employers and policymakers have implemented more programs and policies for working caregivers than researchers have evaluated. Although most programs and policies are developed and implemented within a particular logical framework, it is crucial to have extensive evidence in order to allocate resources effectively and reach this growing population directly. As the population of employed caregivers and their need for support continue to grow, academic institutions and other researchers can further the state of the evidence base by improving baseline needs data and surveillance for working caregivers as well as undertaking program and policy research.<sup>53,54</sup> States have collected leave utilization data, but there is much opportunity for additional data collection and analysis to illustrate how the use of various leave types are associated with the use of other services and with health and financial outcomes for caregivers and care recipients.<sup>55,56</sup> Inclusion of evaluation components in new programs and policies is another important step for improving the evidence base and more effectively supporting the caregiver population.

### **Conclusion**

Improving the health and quality of life of working caregivers of older adults is a public health issue and an opportunity to achieve health equity. Policymakers, employers, and researchers are all in a position to advance the state of the issue by developing and implementing new solutions and identifying best practices. Policymakers have an opportunity to expand family leave benefits or reduce the restrictions on the availability of leave for caregiving. Employers can improve outcomes by providing services, implementing programs, and enforcing policies in support of their caregiver employees. They can attend to specific needs and lessons learned by ensuring that employees are made aware of services and that all offerings are dynamic as the population of working caregivers and their needs continue to change. Researchers can support the expansion of the evidence base by undertaking evaluation efforts on new programs and policies. As SHAs seek to achieve the triple aim of health equity in their jurisdictions, they have a significant opportunity to encourage and support all of these players in aiding this expanding population.

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