# Working While Caring: Innovations and Interventions to Support Caregivers in the Workplace

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## **EXECUTIVE SUMMARY**

As the United States trends towards an older population and more people living with chronic health conditions and disabilities, the number of people who need or will need caregiving assistance continues to grow. Currently, an estimated one out of five adults in the nation's labor supply identifies as a caregiver. Most caregivers are employed, usually full-time. There are many more who would prefer to work but their caregiving responsibilities make it impossible.

Studies repeatedly find that caregivers who are employed are under a great deal of strain, often with negative impacts on their health and employment. Contributing to this situation are a set of barriers, operating within our health care system (mainly though not exclusively in long-term care), the care payment system, community services systems, and in the workplace. Some barriers are related to public policy decisions and regulations. In 2022, the Rosalynn Carter Institute for Caregivers published *Invisible Overtime*, detailing key facts for employers about caregiving in America and opportunities for improving supports for employees who are or will become caregivers.

This report is a follow-on to *Invisible Overtime*. It describes how one group of employers collaborated to: 1) raise their own awareness of the issues facing employees who are working while caregiving, 2) identify options for supporting current and future caregivers, and 3) develop fit for purpose, practical solutions. In this report, there was mutual interest among the employers in improving supports for their employees who have positions that preclude them from working remotely, and hourly employees who may have more limited compensation and benefits. Five small to mid-sized employers in southeast Michigan, who share the labor supply, came together to participate in the inaugural Innovation Lab. The Innovation Lab is a problem-solving approach in which different bodies of knowledge and experiences are applied to complex challenges to foster novel and sustainable solutions.

From the outset, the Working While Caring team and participating employers emphasized the value of solutions that move the needle rather than check the box. The goal of moving the needle is to change the underlying dynamics of the problem, which includes considering systemic change. For example, a check the box approach could entail raising employee awareness about psychosocial counseling that is already available through an existing Employee Assistance Program (EAP). A move the needle approach could involve creating EAP vendor performance criteria mandating certain types of caregiver support services (e.g., specialized counselor training and coordination with

Working While Caring's inaugural Innovation Lab collaboration included:

- Raising awareness of the issues facing employees who are working while caregiving
- Identifying options for supporting current and future caregivers
- Developing fit for purpose, practical solutions

community-based service providers) and instituting standard metrics measuring caregiver and care recipient outcomes.

Innovation Lab members participated in a review of current research evidence prepared by content experts, which included results of systematic reviews of caregiver interventions and meta-analyses, reports of business group employer best practices, and an environmental scan of home and community-based services. Members then reached consensus on a vision for the workplace; improving the ecosystem of supports for employee caregivers to create a more caregiver-friendly workplace.

Based on their review of best practices and research evidence, Lab members identified a combination of demand side and supply side interventions. Some of these interventions are incremental improvements in existing resources, such as their Employee Assistance Programs (EAP). Others represent a departure from currently available resources and practices. An innovative cross-employer shared Navigator role was proposed. This role is designed explicitly to support employee caregivers, using resources and supports inside and outside of the workplace, including developing partnerships with community-based services. The next step for the Lab members is a proposed pilot test that will engage them in the design, implementation, and evaluation of this concept.

An estimated 53 million Americans age 18 or older are caregivers to one or more persons who need help due to aging, illness and/or disability.<sup>1</sup>

## INTRODUCTION

As the United States (US) trends towards an older population and more people living with chronic health conditions and disabilities, the number of people who need or will need caregiving assistance is also growing. Family members and friends play an important part in providing caregiving assistance such as helping with health regimens, navigating care systems, and performing activities of daily living. An estimated 53 million Americans aged 18 or older are caregivers to one or more persons who need help due to aging, illness and/or disability.<sup>1</sup>

While caregiving certainly is not new, it is in transition and arguably becoming more challenging. Today's caregivers may find themselves helping people with complex health conditions requiring them to perform multiple and sometimes complicated care tasks, assuming responsibilities lasting months or years, traveling long distances to provide care, and/or contributing financially towards care expenses. Also, with a high percentage of women in the labor force, most caregivers are juggling responsibilities both inside and outside the home. An impressive 60% of caregivers have a job, and most often the job is full-time. Based on estimates from available national surveys, a staggering one out of five adults in the US labor supply identifies as a caregiver. 2,4,5

Many people, employed or not, place a high value on personally caring for someone who is aged, ill, or disabled, and many caregivers also place a high value on continuing to work. Yet these two highly valued social roles are at times incompatible and difficult to manage. Research consistently finds that most employee caregivers experience significant physical, mental, and/or financial strain, upending the quality of their lives and threatening their effectiveness as caregivers. More than half of all caregivers report that caregiving responsibilities have taken a toll on their careers and/or jobs. Many employees who are caregivers leave a full-time job for a part-time one, quit a job to find a less demanding one, or relinquish work entirely, actions that place caregivers, their families, and their employers at economic risk. Caregivers lose an estimated \$522 billion in wages each year due to caregiving, and employers lose an estimated \$33 billion per year due to employees' caregiving responsibilities.

## A CALL TO ACTION

The Rosalynn Carter Institute for Caregivers (RCI) Working While Caring Initiative is focused on strengthening employer capacity to support their employees who are or will become caregivers, including helping these employees stay attached to employment. In 2022, RCI published *Invisible Overtime*, providing employers with key facts about employee

caregivers, their struggles with labor force participation, and the outcomes and costs of caregiving for both employees and employers. The report described a looming crisis caused in large part by a flawed ecosystem of institutionalized supports and resources: long-term care and community-based services (including home health care) that are fragmented, hard to navigate, and in short supply; 10 chronic shortages in the direct care workforce; 10 an increasing demand for paid caregivers with the aging of the baby boomers; 11 and gaps in Medicare, Medicaid, and commercial insurance coverage that significantly limit the affordability of care.

Contributing to this projected crisis is a patchwork of federal and state regulations and programs that are confusing and have left many caregivers without the support they need. Some programs involve a substantial employer investment in both time and resources. The US Family and Medical Leave Act (FMLA) created the nation's largest job protection and employee leave program. It has helped millions of workers to take time off without losing their jobs. 12,13 However, some employees are ineligible and/or cannot afford to take unpaid leave. Several states have enacted paid family and medical leave policies, yet many are still left without adequate protections due to variations in eligibility provisions (e.g., which groups of workers are protected and how "family" is defined) and benefit payment amounts. 14-16 Several other policies are in place or on the horizon and will further change the landscape for employee caregivers and their employers. These include the self-directed care provisions of some state Medicaid plans, which allow beneficiaries to compensate family caregivers, <sup>17</sup> the Center for Medicare and Medicaid Services 2024 proposal to pay health care providers to train family caregivers to assist with care, <sup>18</sup> and the 2022 National Strategy to Support Family Caregivers, <sup>19</sup> an expansive set of more than 500 recommendations of the Advisory Councils established by the RAISE Family Caregiving Act and the Supporting Grandparents Raising Grandchildren Act and stakeholder advisors.3

Caregivers are a large segment of the current and future labor supply. They are essential to business success. Research tells us that before the Covid 19 pandemic, the status quo of supports and resources was not working for caregivers or their employers. Since the pandemic, the greater availability of remote and hybrid work is likely to have helped some employees to better balance caregiving and work. However, significant challenges remain for employee caregivers and employers, and the pace at which effective solutions have emerged has been far too slow. Among the greatest and most challenging areas of need is for solutions geared towards employee caregivers who are required to perform work onsite (such as health care providers, teachers, retail

"Gesher Human Services joined the Innovation Lab to assist our staff and the individuals and families that we serve in identifying promising approaches to supporting caregivers in balancing caregiving, work, and wellness.

The experience has provided us with a roadmap for piloting some approaches to supporting our team and community that we had not considered before."

- Gesher Human Services

salespeople, transportation personnel, and workers in manufacturing), and those paid hourly, who do not accrue the same benefits as salaried employees. Another area of need is practical information for small and mid-sized employers. Much of the current research on caregiving and business group analyses has been oriented towards the large, self-insured employer audience, but these results do not necessarily generalize to employers that are smaller and less resourced.

This report is a case study documenting how one group of employers, located in the same geographic region of the US and sharing similar labor supply and ecosystem challenges, collaborated to: 1) raise their own awareness of the issues facing employees who are working while caregiving, 2) identify options for supporting current and future caregivers, and 3) develop fit for purpose, practical solutions. The inaugural Employer Innovation Lab was established by the Working While Caring initiative of the Rosalynn Carter Institute for Caregivers.

## THE INNOVATION LAB

#### **Process and Participants**

The inaugural Innovation Lab included small and mid-sized employers from the for-profit and non-profit sectors in southeast Michigan, each of which had many employees in jobs requiring on-site work and paid hourly.

The Innovation Lab represents a problem-solving approach designed to respond to the increasing complexity of many contemporary challenges. It is based partly on the assumption that different bodies of knowledge and experiences are important for creating novel and sustainable solutions. Stakeholders with a shared interest in a topic or concern come together to collaboratively learn from each other, share and acquire new knowledge, spark ideas about new solutions and strategies, and coalesce around action plans. Some Innovation Labs continue to bring participants together to co-learn and collaborate through a phase of pilot-testing or implementing one or more innovations. This process encourages participation and openness of ideas in a non-competitive context with rules to ensure confidentiality. Each Innovation Lab meeting is moderated by a group facilitator and aided by content experts who assist in organizing materials and responding to group requests for information. Most of the Lab members' work occurs during Lab meetings, supplemented by pre-work. The Lab is time-limited and occurs away from the workplace either in-person or virtually, with a cadence that is determined by the participants and the context.

#### **Problem Scoping**

process by providing a shared knowledge base and a lens through which employers could review the situation in their own companies, frame the issues, articulate priorities, and begin the process of developing solutions. During the first session, the group discussed the costs and benefits of maintaining employment while caregiving, which included reflections on both personal and employment impacts. Lab members also were presented with the Working While Caring perspective on the caregiving ecosystem, which includes the groups and institutions that can influence the experience of caregivers at work and home and in their communities (Figure 1). From the outset, the Working While Caring team emphasized the value of solutions that move the needle rather than check the box. The goal of moving the needle is to change the underlying dynamics of the problem, which includes considering systemic change. For example, a check the box approach could entail raising employee awareness about psychosocial counseling that is already available through an existing Employee Assistance Program (EAP). A move the needle approach could involve creating EAP vendor performance criteria mandating certain types of caregiver support services (e.g., specialized counselor training and coordination with community-based service providers) and instituting standard metrics measuring caregiver and care recipient outcomes.

The Invisible Overtime report<sup>9</sup> helped to support the Innovation Lab

Lab members initially discussed how and why their organizations' priorities and values intersected with caregiving. The organizations had various reasons for participating in the Innovation Lab, but all felt the pressures of continuing to attract and retain talented employees. They were also acutely aware of the heightened social, psychological, and economic strains employees were experiencing because of the pandemic.

Employers also shared what they had already learned about caregivers in their respective companies. Each company was at a different point in their understanding of caregiving challenges within their employee populations, and the use and effectiveness of existing supports and resources within their own organizations. In most cases, formal information-gathering was limited, and information was often gained from informal discussions with employees or Employee Resource Groups (ERG) addressing adjacent topics such as disability and inclusion.

#### **Working While Caring Vision**

Employers are an important part of a larger interdependent ecosystem



Figure 1. The caregiving ecosystem

To advance this discussion within the Innovation Lab, content experts presented evidence-based information about the costs and benefits of working while caring (Table 1).

Table 1. The Costs and Benefits of Maintaining Employment While Caregiving

<ul> <li>Social isolation/limited social participation</li> <li>Less personal health maintenance</li> <li>Difficulty maintaining a work schedule and work routine</li> <li>Difficulty maintaining optimal work performance and productivity</li> <li>of life</li> <li>More affordable than paid caregiving options</li> <li>Less economic disruption</li> <li>Less career disruption</li> <li>Work skills improve caregiving skills and vice versa</li> </ul>	Examples of Personal and Career Costs	Examples of Personal and Career Benefits			
<ul> <li>Diminished career opportunities</li> <li>Reduced earnings and accumulation of wealth and benefits</li> <li>Increased out-of-pocket expenses</li> <li>caregiver and/or care recipient</li> <li>Source of respite from caregiving duties</li> <li>Employment can be a source of social connection/social support</li> </ul>	<ul> <li>energy, and attention</li> <li>Demand overload</li> <li>Emotional/psychological distress</li> <li>Physical health strain</li> <li>Social isolation/limited social participation</li> <li>Less personal health maintenance</li> <li>Difficulty maintaining a work schedule and work routine</li> <li>Difficulty maintaining optimal work performance and productivity</li> <li>Strain on work relationships</li> <li>Diminished career opportunities</li> <li>Reduced earnings and accumulation of wealth and benefits</li> </ul>	<ul> <li>in need</li> <li>Care is more personalized/aligned with values</li> <li>Enables involvement in care decisions</li> <li>Contributes to care recipient's health and quality of life</li> <li>More affordable than paid caregiving options</li> <li>Less economic disruption</li> <li>Less career disruption</li> <li>Work skills improve caregiving skills and vice versa</li> <li>Access to benefits, services, and resources for caregiver and/or care recipient</li> <li>Source of respite from caregiving duties</li> <li>Employment can be a source of social</li> </ul>			

The group of employers identified several key takeaways from this process.

- Caregiving for an ill, disabled, and/or aging person is part of the social fabric of American life; it is important and not going to go away.
- The supports people usually turn to for help, such as long-term care providers, Medicare, and Medicaid, are insufficient, and many caregivers have dissatisfying experiences interacting with them. These experiences contribute to problems that can spill over into the workplace.
- Ordinary work demands and pressures can and do spill over into the personal lives of employee caregivers in ways that are detrimental to them and those they assist. While some of these cannot be avoided, there may be ways to minimize their negative impacts.
- Cultural factors, such as the perceived stigma attached to caregiving, as well as a general lack of awareness about caregiving, what it means and who is affected, add to friction between employee caregivers, their managers and co-worker peers.
- Most employers offered resources and services that have the potential to support employee caregivers, but personal and organizational barriers may hinder their use and effectiveness.
- Despite the challenges of working and caregiving, many employees feel caregiving is rewarding and they feel honored to provide care.

## BUILDING THE CASE FOR INVESTING IN CAREGIVER SUPPORTS

Lab members anticipated that convincing an organization to commit to a targeted initiative for employee caregivers would require a better understanding of what was already known about how to support this population, and which resources contribute to achieving success. Some Lab members felt it was necessary to lay the groundwork for buy-in from decision-makers and the employees themselves. Thus, the group engaged in a process aimed at achieving clarity about the specific objectives of a caregiver support initiative, the business case for action, and the effectiveness of different strategies and interventions.

Based on information from *Invisible Overtime*, other caregiver research, and Lab members' own professional and personal experiences, Lab members had two critical observations:

- Caregivers and caregiving needs are highly variable. These needs reflect the wide range of differences in family norms and values, caregiver age, gender, race and ethnicity, the care recipient's health condition(s) and health trajectory, caregiver and care recipient proximity, the availability of economic resources (e.g., income and long-term care insurance), and the availability of services such as medical care.
- 2. Disparities exist in caregiving demands and caregiver and care recipient outcomes. People of color, people with lower incomes, and women provide caregiving at the highest rates. Several Lab members had already committed to programs to increase diversity, equity, and inclusion in their organizations and wanted to understand how supporting caregivers could intersect with these plans. The existing infrastructure of these and other work/family initiatives could facilitate or limit targeted caregiver support efforts.

Additionally, members of the group discussed common and emerging sources of friction between caregiving and working, and the degree to which they were considered modifiable. Friction points increase the risk of caregiver strain and negative effects on employment. When discussing caregiving/work friction points, Lab members contributed several candid insights related to working patterns and attendance policies, resource limitations, navigation of existing systems, and stigma:

 Requirements to be on-site and/or assignments for specific shifts are common sources of friction and worsened by staffing shortages. In certain positions, there is little or no relief pool, and employees are "Our Business Resources Groups also offer needed support for our caregivers and veterans, however, each caregiving situation is unique, and finding the right balance often involves a combination of support from employer, understanding from coworkers, and resources and support systems.

We are continuing our journey for needed caregiving support that can aid our valuable associates and help us attract and retain associates with caregiving benefits."

– Carhartt

- already doubling up on shifts. Some resources are available, such as shift exchanges, but they can be difficult to use.
- In some of the unionized environments, "time off" policies are
  determined by collective bargaining. When multiple employees
  request time off, the requests are granted based on employee
  seniority, which can work against some employee caregivers.
- During key production periods, it is challenging for managers to be flexible about shifts or requests for time off.
- There is growing tension between salaried and hourly staff, which
  has been amplified since the pandemic, as salaried employees
  gain more flexibility (e.g., opportunities for remote or hybrid
  work). Providing hourly staff the opportunity for off-site work is
  not always possible.
- Some managers are not fully aware of benefits and resources available for employee caregivers, and they may not know how to respond appropriately to employee requests for accommodations.
- Attendance/absentee policies requiring employees to accumulate time before qualifying for time off can be especially challenging for employee caregivers. In some cases, it may be possible to modify time accumulation requirements or make other adjustments (e.g., time off donation pools).
- When employees do not have sufficient financial resources, they may be more vulnerable to certain problems. For example, they may be less willing or able to take unpaid time off even when needed. Or they may lose more work time because they do not have the resources to cope with emergencies at home.
- Many employees have difficulty navigating the care system, which adds to their strain and takes up time both at home and during the workday.
- Some employees may be reluctant to disclose they are caregiving and ask for help from managers and/or coworkers. Some may experience stigma because of their caregiving.

The group felt that, realistically, certain aspects of workplace structure and culture were unlikely to change in the near-term and that some changes assumed to accommodate employee caregivers, such as hybrid or remote work and other flexible work arrangements, are difficult to apply to workers whose jobs require them to be on-site or governed by collective bargaining agreements. These concerns did not mean such options were off the table, but that they will take much longer to implement.

"VOAMI is interested in ensuring that caregivers have a space at the organization that honors their caregiver commitments while also meeting their professional goals and objectives."

- Volunteers of America Michigan

Another important point was that organizational resources and services were already available to employees. For example, in addition to EAP counseling, which all organizations offered, some of the organizations provided support for ERGs, employee shift exchanges, paid time off banks, small grants to cover personal expenses during a crisis, and financial and life planning assistance. However, the organizations did not have adequate information about how many caregivers have accessed these resources and services, and whether they helped to solve the caregivers' problems.

Innovation Lab members also felt it was important to recognize that many caregiving issues are related to the weaknesses of the external care environment, and these conditions may be difficult to overcome in the near-term. A limited supply of home care providers and affordable high-quality care, the pervasive fragmentation in services, and the challenge of coping with an unresponsive system of providers and payers, individually and collectively, increase the strain on caregivers and can limit the success of employee caregiver support interventions.

For Lab members, the formidable constraints of on-site job requirements and limitations of the external care environment underscored the importance of focusing on identifying changes that could be implemented immediately. Several considered forming and supporting multi-stakeholder groups in their organizations to address caregiving concerns, as well as addressing barriers to accessing and using existing supports. One idea was to implement campaigns to raise awareness of caregiving among employees (caregivers and non-caregivers) and managers, and to improve access to information about benefits and services. Several members mentioned that they had good working relationships with their vendors such as their EAPs and felt that they would be willing to partner on targeted efforts to improve caregiver resources and services. Finally, in addition to strengthening existing supports and considering new ones, Lab members expressed an interest in considering solutions that prevent caregiver problems from occurring in the first place or keep them from becoming more difficult to solve.

## **CREATING A SHARED VISION**

Lab members agreed that, from the employer perspective, the timing was right to undertake change, citing three compelling reasons:

- 1. The importance of recruiting, hiring, and retaining talented workers.
- 2. Commitments to achieving diversity, equity, and inclusion, which intersect with employment issues facing caregivers from minoritized groups.
- 3. The ongoing process of reconsidering how work can be organized to make jobs more attractive coinciding with the Covid-19 pandemic, which has led to more intentional out-of-the-box thinking.

Innovation Lab discussions were aimed at achieving consensus on a shared vision for the workplace including the goals and objectives Lab members hoped to accomplish and, also, vetting different approaches for advancing their vision. The process involved several rounds of discussion, reacting to ideas generated from research and their own real-world experience, and evaluating approaches based on the results of scientific reviews and best practices.

Lab members were presented with a variety of possible ideas or approaches ranging from relatively specific caregiving problems, such as reducing difficulty finding a home care provider, to organizational-level

problems such as reducing presenteeism and absenteeism related to caregiving, and broader system-level problems such as increasing caregiver economic security and stability (which could include earnings, housing costs, expenses, etc.). These are shown in Figure 2.

#### Specific Systemic

- Provide a welcoming and supportive culture
- Reduce work and caregiving friction
- Reduce caregiving I ogistical challenges
- Reduce caregiving navigational challenges
- Reduce caregiving task challenges (e.g., medical care tasks)
- · Reduce emotional strain
- Reduce financial strain
- Improve access to community- based care

- Reduce presenteeism, absenteeism
- Reduce turnover (reducing the size of the group that stays vs. the portion that turns over rapidly)
- Enhance recruitment, hiring and retention
- Increase employee engagement with supports
- Work towards employer of choice/best place to work designation

- Support a business and community-wide effort to recruit, hire and retain employee caregivers
- Promote/protect better caregiver health and well-being
- Increase employee economic security and stability
- Improve and strengthen the relevant systems of community- based resources and services

Figure 2. Solutions to caregiver needs, ranging from narrow and specific solutions to broad system-level solutions

Following this discussion and further elaboration of ideas or approaches for a shared vision, a confidential poll was conducted and the options receiving the most votes were adopted. The Innovation Lab vision was expressed as a single goal with primary and secondary objectives (Table 2).

## **WORKING WHILE CARING INNOVATION LAB PRIORITY SETTING**

#### **OVERALL GOAL**

To mobilize employers to improve the ecosystem of supports for employee caregivers by implementing policies and practices for a caregiver-friendly workplace (system and culture focus)

#### **PRIMARY OBJECTIVES**

- conduct an environmental scan
- promote awareness of existing resources

#### **SECONDARY OBJECTIVES**

- prepare a business case for action
- implement best practices that also contribute to hiring and retention

#### **IDENTIFIED INFORMATION GAPS**

- describe the context external to the company
- identify existing benefits, resources and supports inside the company

Table 2. Working While Caring Innovation Lab Priority Setting

The term "caregiver-friendly workplace" can sound informal to some. However, it is a key concept in the research literature reflecting two related perspectives (Table 3).

Caregiving Friendly Workplaces (Canadian Framework)	Work-Life/Work-Family Interventions (US Framework)
Deliberate organizational changes in policies, practices or the target culture, to reduce work–family conflict and/or support employees' lives outside of work. Includes modifications to organizational structure, policies, or programs for the purpose of supporting employee work-life balance and reducing conflicts for employee caregivers. <sup>20</sup>	Interventions aimed at reducing work–life and work–family conflicts to enhance the well-being and effectiveness of employees and their families, and the organizations in which they work. 21 Structural interventions refer to the extent to which organizations adopt a menu of formal work–life policies. Cultural interventions refer to the degree to which leaders and all members actively value positive work–life relationships and work–life fit as a condition and the degree to which the organizational culture has norms that employees perceive as signaling values that individuals will not face negative consequences (job loss, lower pay or promotion) if they have dual high involvement in caregiving and breadwinning or regularly allocate time to nonwork interests. 21

Table 3. Concepts Adapted to Inform the Innovation Lab Members' Main Goal

## **IDENTIFYING PROMISING OPTIONS**

To familiarize Lab members with possible intervention options, they participated in a review of current research evidence prepared by content experts, which included results of systematic reviews of caregiver interventions and meta-analyses, prioritizing those addressing caregiving and employment. <sup>22-26</sup>
Additionally, they reviewed employer best practices using reports from business groups, and the results of an environmental scan of home and community-based services.

Lab members learned that caregiver research was far from definitive. It is characterized by studies that had different research objectives, caregiver populations, and outcome metrics. There were also methodological weaknesses and under-researched topics, such as the value of respite care for caregivers. Ultimately, five types of interventions were considered to have the most promising evidence for use in employee populations and for improving employment-related outcomes:

#### 1. Flexible Work Arrangements

Of all the strategies employee caregivers use and find effective, the most common are reducing hours to less than full-time or limiting overtime and working at times of the day involving fewer people and/or less monitoring (e.g., night shifts). Studies of alternate arrangements show caregivers prefer reduced hours over condensed workweeks or job-sharing, which compress job demands into shorter time frames. A downside to part-time work is its effects on earnings and access to benefits.

#### 2. Caregiver-friendly Workplace Interventions

This is a broader set of multi-level interventions in which caregiver inclusivity is valued and conveyed through formal and informal practices and procedures, that (at minimum) do not discriminate against caregivers and attempt to accommodate their needs related to providing for care recipients.

#### 3. Psychotherapy/Counseling

Access to psychological interventions that improve coping and communication have multiple benefits for caregivers. The strongest evidence is for cognitive behavioral therapy (CBT). Including an educational component with psychotherapy would teach caregivers about managing care and may improve caregiver outcomes. Effectiveness is reduced if barriers to accessing and using mental health services are not addressed.

#### 4. Connection to Formal Services/Care

Having at least one formal caregiving support service such as a comprehensive assessment is beneficial to maintaining employment for caregivers, especially those assisting persons with dementia or frail elderly. A comprehensive assessment of the care recipient's needs supports the process of determining which services are appropriate. Research also finds that care management is beneficial to both caregivers and care recipients. It focuses on the patient's actual care and helps them transition between treatments and stages of care. It is different from case management (which refers to an overall plan for the care recipient), for which evidence is weak.

## 5. Engaging Caregivers in Decision-making About the Care Recipient's Care and Support

Research suggests that strengthening ties between health care providers and caregivers, including integrating the caregiver into the care team, is beneficial to caregivers and care recipients. However, significant barriers to achieving this integration remain and will require changes at the health care system, health care provider and caregiver levels. Recent efforts to compensate medical providers to engage family caregivers of Medicare beneficiaries is an example of such change.

In terms of the employer best practices literature, few interventions had been evaluated. Many of the ideas discussed in this literature were considered unlikely to move the needle to alleviate caregiving challenges. For example, some business groups have emphasized promoting employee caregiver utilization of EAPs. Though most EAPs offer some form of psychological counseling and resources, such as financial,

"I have benefited from being a part of the discussion group led by the Rosalynn Carter Institute for Caregivers. Participating with leaders from other organizations, sharing individual caregiver perspectives, and learning about and informing the research on the important subject of caregiving, I hope will positively impact employees, employers and all of our communities."

- Zingerman's Community of Businesses

and end of life planning tools, EAP counselors typically do not receive specific training in interventions to support caregivers of aging, ill or disabled individuals, and their services are general instead of targeted to addressing certain needs (such as navigational assistance).

Contracting with concierge caregiver support providers has been identified as another possible approach. These are becoming more prevalent among large employers mainly for their salaried or more highly paid employees. Using the service may require employee co-payments and the number of sessions approved per employee sometimes is capped. Concierge vendors typically offer navigational and administrative help for caregivers among other services, perhaps reducing the time and effort (and potentially the strain) involved in caregiving and, of interest to employers, reducing costly lost work time and productivity. Currently, there are no systematic reviews of outcomes, which would include data comparing this intervention to others.

## **DEVELOPING A PLAN**

Lab members nominated a series of ideas for further discussion and vetting. Throughout this process, the Working While Caring team advocated for thinking about which options could be piloted across multiple employers, have value to the participating organizations, and generalize to other small and mid-sized employers.

Overall, the favored approaches to achieving their agreed goal and objectives had four defining features:

- 1. Practicality in the sense of incrementally chipping away at the problem and taking advantage of infrastructure already in place.
- 2. Organization-specific roll-out and implementation plans that consider organizational size, locations, population characteristics, and the prevalence of in-person jobs.
- 3. A preference for multiple interventions to address the variability and complexity of caregiving challenges.
- 4. An interest in piloting innovative approaches.

Articulating their vision for achieving a stronger caregiver-friendly workplace, Lab members identified a combination of demand side interventions and supply side interventions (Table 4). Demand side interventions are aimed at increasing awareness of caregiving (including among employees who are caregivers but do not see themselves as such), identifying caregiver needs, educating staff and managers about supporting employees who are caregivers, and identifying clear channels to facilitate access to information about company and community benefits and resources. Supply side interventions are aimed at improving the inventory of services and resources available, their utilization and effectiveness. Importantly, the combination of approaches is a deliberate attempt to create and sustain a caregiver-friendly workplace.

Some of the interventions discussed were already in place and others were in the planning stages. To reflect how far each organization was on the pathway to adopting and offering each type of intervention, Table 4 classifies each organization as currently contemplating, acting, or optimizing the intervention, or not considering the intervention (which is indicated by a blank cell). Contemplating is the earliest phase, and it is mainly exploratory. Acting indicates that steps are being taken to plan, develop and implement. Optimizing refers to interventions already in place that are going through an improvement phase.

All five of the organizations indicated support for interest groups, whether in the form of an ERG or, in one case, a business group, which involves representatives from each of the relevant departments. Several Lab members were already involved in creating a new website portal that would centralize pertinent information

for employees and managers and include links to supports both internal and external to the organization. Several were initiating campaigns and activities to improve awareness of caregiving, some of which were aimed at informing as well as normalizing and destignatizing caregiving.

Each organization expressed an interest in partnering with their EAPs to strengthen its role in providing accessible, high quality, and comprehensive supports for caregivers including establishing relationships with community-based service providers such as Area Agencies on Aging, rehabilitation facilities, and medical equipment supply vendors. Additionally, all five of the employers were taking concrete actions to review and assess current benefits offerings and to better support caregivers, including reducing barriers to access and use, and improving equity.

On the supply side, two ideas for innovations were introduced. One would create and implement a shared Navigator position designed to be both specialized and achieve economies of scale. This concept is described in more detail in the next section. Another idea was to identify community providers, such as respite care organizations, which could offer services that are tailored specifically for employees of these companies. For example, some respite care providers have designated drop-off and pick-up times that are not synchronized with employee shifts. Lab members were interested in arrangements that could better accommodate their employee caregivers.

Table 4. A list of demand and supply side interventions to support working caregivers and management and evaluation tools to determine the impact of these interventions

	Co. A	Co. B	Co. C	Co. D	Co. E			
Demand Side Interventions								
Employee Resource Groups	А	А	С	С	0			
Website Portals	С	А	А	С				
CG Awareness-Building/Education Activities	А	А		А	С			
Supply Side Interventions								
EAP Strengthening/Specialization/Performance Standards	С	A	А	A	А			
Benefit and Policy Actions (harmonizing, tailoring, reinforcing)	A	А	А	А	А			
Life Services Support/Navigator	С	С	С	С	С			
Partnering with Community Providers	С	С	С	С	С			
Management and Evaluation								
Population Needs Assessments	С	А	С	С	А			
Stakeholder Advisory Board	С	С	С	С	С			
Evaluation of Impact and ROI	С	С	С	С	С			

Contemplating (C), Acting (A), Optimizing/Continuously Improving (O)

## **NEXT STEPS FOR THE INNOVATION LAB**

In the final meetings of the inaugural Innovation Lab, members formulated a plan to develop and pilot-test an innovation with the potential to create a solution that generalizes to other small to mid-sized employers with significant numbers of hourly and front-line employees.

The proposed pilot intervention will involve the design, implementation, and evaluation of a Navigator Program to support employee caregivers. The proposed Navigator Program is designed to address employee caregivers' unmet needs for timely and effective caregiving assistance from the health care system, home and community services, and employers, as well as to prevent or reduce the psychological distress of balancing both roles.

The Navigator Program is envisioned as an explicitly structured and tailored support system for employee caregivers that, if effective, will:

- Reduce the time and effort typically involved in resolving or preventing caregiving challenges.
- Strengthen employee caregivers' psychological health and well-being.
- Mitigate adverse effects on employment and work engagement.

It will be designed by and for stakeholders in the workplace, with significant input from executives, managers, and employees.

Additionally, through targeted communications, manager training, and the integration of existing employee benefits with the Navigator Program, the pilot aims to reduce structural and cultural barriers to seeking and obtaining assistance in the workplace, and strengthen self-efficacy at work for employee caregivers, which is associated with better health outcomes.

The collaborative employer model of sharing program development and implementation costs (e.g., time) and integrating, where appropriate, existing employer-sponsored benefits and offerings, also increases the potential of achieving a positive return on investment for participating employers.

This approach will recognize employee caregivers within the workforce and provide navigational services that will help to connect employee caregivers to needed supports within the organization and the community that are intended to reduce the stress of performing both work and care. Connecting employee caregivers to formal supports can help to protect an employee caregiver's health and attachment to the labor force. In turn, this can help to enhance the quality of care provided to care recipients.

## LESSONS AND RECOMMENDATIONS

There were two main lessons from the Innovation Lab. First, relatively smaller employers with large segments of employees who do in-person work, including those in the for-profit and non-profit sectors, have a valuable perspective to share about the challenges they and their employees face and solutions that are realistic. Secondly, given the opportunity to focus on an issue that could seem overwhelming to some or unrelated to business priorities, these employers are an important source of innovation. The human resources personnel and those tasked with identifying and managing service suppliers are spread thin, and the constraints they operate under often do not afford them the opportunity to take time away from daily demands.

When given this opportunity, Lab members had invaluable knowledge and experiences to share, which they did generously and, perhaps because they are used to doing more with less, they delivered a talent for creative solutions.

This report presented a variety of steps employers can take to create a more caregiver-friendly work environment and community. For employers who are interested in forming Innovation Labs or simply vetting ideas for assisting employees who are or will become caregivers, there are several simple ways to get started, and several more advanced, longer-term strategies to consider:

- Establish an employee caregiving interest group or cross-business stakeholder group, representing a
  diverse range of caregivers and other stakeholders, to serve as a resource to management and other
  employees.
- Know your data. On employee surveys, gather information about caregiver status.
- Conduct an audit of existing policies and services that affect caregivers, vetting alignment with known
  caregiver issues, potential biases, and barriers to their effectiveness and use. Pay close attention to leave
  policies and procedures that may include unnecessary barriers.
- Normalize caregiving. Engage leadership in showing support for caregivers and reducing stigma, and
  ensure that employees and managers know about the benefits and services they now have and how to
  use them.
- Prepare current caregivers and all employees with information about Medicare and Medicaid coverage
  for home care, long-term care and other community-based services, including identifying gaps
  in coverage and options for addressing those gaps (recognizing that there are not solutions to all
  circumstances).
- Train managers on policies and procedures relevant to caregivers and provide them with the resources and support they need to support caregivers.
- Work 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 caregivers
  and their families.
- When preparing requests for proposals (RFPs) and contracts for service suppliers including health care insurers and providers, concierge caregiver firms and EAPs, require inclusion of caregiving-friendly workplace services, evidence-based practices (e.g., CBT for caregiver strain) and mandate reporting on key performance and outcome metrics (e.g., utilization of paid leave, decreasing work hours, presenteeism, and absenteeism).
- Collaborate with your local and regional business groups' efforts to identify gaps in caregiver benefits
  and services, create guidelines for a minimum benefits package, standardize vendor/supplier metrics and
  benchmarking reports, and influence policymaking.

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Onward!



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