Working While Caring

Dr. Jennifer Olsen, CEO
Rosalynn Carter Institute for Caregivers

National Lifespan Respite Conference
September 15, 2022
Our Mission

The Rosalynn Carter Institute for Caregivers (RCI) promotes the health, strength, and resilience of family caregivers at every stage of their journey.
Our Founder

“There are only four kinds of people in the world: those who have been caregivers, those who are caregivers, those who will be caregivers, and those who need them.”

— ROSALYNN CARTER
Our Work

Evidence-based programs to build individual caregiver strength, health, and resilience.

Research, advocacy and partnerships to build supportive structures and systems.
Building a movement: 4Kinds Network

This fall, RCI will launch its first-ever advocacy network to:

• Amplify the voices of family caregivers
• Develop future policy priorities in partnership with caregivers
• Organize, train, and mobilize network members to advocate for change

Join the 4Kinds Network! Email 4Kinds@rosalynncarter.org
Working While Caring

RCI’s research and employer outreach initiative
"The Great Resignation: How employers drove workers to quit"

"The Great Resignation is hitting these industries hardest"

"Why is everyone quitting, and how do I know whether it’s time to"

"What women leading the Great Resignation means for employers"
Raising awareness of challenges faced by caregivers who are working full-time through:

1. Research: We conducted two national surveys; more to come

2. Outreach: We are conducting targeted outreach to employers to identify and develop effective supports

3. Policy: We are seeking to inform public policy initiatives
US workers cares for a family member who is ill, aging, or disabled, and most of these caregiver employees (CEs) are employed in full-time jobs.
Workplace Effects

- 73% had to leave work early or unexpectedly
- 70% had to call out from work for one day
- Nearly 60% had to take two or more days off in a row from work
- Nearly 20% had to quit a job to care for a relative
- More than 40% had to go to part-time work
What would you say is/was the biggest challenge with being employed full-time and managing care for your loved one? / And what is/was the next biggest challenge with being employed full-time and managing care for your loved one?

<table>
<thead>
<tr>
<th>Biggest Challenges – Ranked by 1st Choice</th>
<th>1st Choice</th>
<th>Combined 1st/2nd Choices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional stress of handling both job and caregiving responsibilities</td>
<td>39%</td>
<td>62%</td>
</tr>
<tr>
<td>Too time-consuming handling both job and caregiving responsibilities</td>
<td>14%</td>
<td>24%</td>
</tr>
<tr>
<td>Lack of time for self-care</td>
<td>13%</td>
<td>27%</td>
</tr>
<tr>
<td>Difficulty with scheduling loved one’s doctor’s appointment/treatments around job</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>Dealing with interruptions or distractions related to my loved one’s care while at work</td>
<td>6%</td>
<td>16%</td>
</tr>
<tr>
<td>Lack of a support system/assistance at home with caring for loved one</td>
<td>5%</td>
<td>12%</td>
</tr>
<tr>
<td>Difficulty affording care for loved one</td>
<td>4%</td>
<td>10%</td>
</tr>
<tr>
<td>Unable to get time off work or other accommodations from employer to care for your loved one</td>
<td>3%</td>
<td>9%</td>
</tr>
<tr>
<td>Employer, supervisor, or co-workers not understanding your situation</td>
<td>3%</td>
<td>9%</td>
</tr>
<tr>
<td>Unable to keep up with job demands or standards of performance at work</td>
<td>3%</td>
<td>8%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
<td>2%</td>
</tr>
</tbody>
</table>
## National Caregivers

<table>
<thead>
<tr>
<th>%Yes</th>
<th>National Caregivers</th>
<th>Ages 18-44 (43%)</th>
<th>Ages 45-54 (24%)</th>
<th>Ages 55-70 (33%)</th>
<th>Non-Hispanic Whites (68%)</th>
<th>People of Color (32%)</th>
<th>Hispanics (13%)</th>
<th>Blacks (12%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quit job</td>
<td>19%</td>
<td>23%</td>
<td>20%</td>
<td>14%</td>
<td>16%</td>
<td>26%</td>
<td>30%</td>
<td>21%</td>
</tr>
<tr>
<td>Reduce hours</td>
<td>44%</td>
<td>57%</td>
<td>40%</td>
<td>29%</td>
<td>39%</td>
<td>54%</td>
<td>67%</td>
<td>53%</td>
</tr>
<tr>
<td>or go part-time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staying in your job longer than you may have wanted</td>
<td>40%</td>
<td>46%</td>
<td>39%</td>
<td>33%</td>
<td>36%</td>
<td>47%</td>
<td>55%</td>
<td>46%</td>
</tr>
</tbody>
</table>
Invisible Overtime

This white paper explores the complex realities facing millions of caregiver employees, how their dueling responsibilities affect the workforce and economy, and how employers can and must be a part of the solution.

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
Invisible Overtime

Nearly one-third of caregiver employees voluntarily left a job at some point during their careers because of their caregiving responsibilities. The main reasons were:

• unable to find affordable paid help (53%)
• unable to find high quality help (44%)
• difficulty meeting work demands due to increased caregiving responsibilities (40%)

Most (80%) felt caregiving had affected productivity, often preventing them from performing at their maximum capability (Fuller & Raman, 2019)
Invisible Overtime

Highlights from the research:

• Interventions are not designed based on the needs of employed caregivers

• FMLA is often unpaid, limited to certain employees and care recipients and underused

• Other benefits some employers have experimented with include alternative work arrangements, navigation and referral support benefits and services, EAP, respite and crisis care, tax-deferred savings accounts, LTC insurance

• Evidence of effectiveness is missing

• Most of the limited research and evaluation occurred pre-pandemic
What Employers Should Know

IT’S NOT EASY BEING A CAREGIVER

Caregiving is a multifaceted and varied experience and there are substantial differences across workplaces and workforces.

OUR HEALTHCARE SYSTEM IS FRAGMENTED + EXPENSIVE

While the private sector can do more to recognize and support their employee caregivers, they cannot solve all the challenges stemming from the fragmented and expensive long-term care system in the U.S.
Caregiving Typology

We have launched an initiative designed to characterize typologies of family caregiving related to duration, intensity, and change over time.

**Goal:** Strengthen programs and policies for family caregivers by designing and targeting supports that directly meet the needs of caregiver typologies.

**Process:** To validate the typologies, an expert stakeholder panel and three caregiver focus groups will advise on typology development.

**Guiding Questions:**

- Do these typologies resonate with caregivers and expert stakeholders?
- What are the experiences of caregivers in terms of intensity, burden and duration by recipient condition?
- Are there social characteristics of caregivers that modify the typology?
Innovation Labs

Innovation labs will be organized in which invited stakeholders spend time, through expert facilitation, focusing on the effects, challenges, and opportunities to improve and strengthen supports for employee caregivers.

The innovation labs will:

• Facilitate dialog among workplace stakeholders
• Focus on the challenges and effects of working caregivers
• Begin with information gathering through surveys and/or focus groups
• Support action planning that includes piloting of supports
• Involve a series of eight sessions to explore opportunities to support caregivers
What's Next for Employers

WE’RE PARTNERING WITH EMPLOYERS

With a goal of **piloting and evaluating a range of benefits** that could aid full-time employees in distinct industry sectors who are caring for a loved one at home.

WHAT EMPLOYERS CAN DO

Employers can be **an influential voice in advancing structural public policy reforms** that move caregiver concerns from the margins to the center, resulting in a healthier, engaged, and productive workforce.
RCI Publications

Recalibrating for Caregivers:
Recognizing the Public
Health Challenge

Working While Caring: A National Survey of Caregiver Stress in the U.S. Workforce
Key Findings
September 28, 2021
Elizabeth Harrington, Partner
Bill McInturf, Partner

Invisible Overtime:
What employers need to know about caregivers
By Debra Lee, MIA, PhD
TAMU/HealthCare Region on Health, Work and Productivity
Tyler Clinical and Translational Science Institute
Thank you