

# Working While Caring

Dr. Jennifer Olsen, CEO  
Rosalynn Carter Institute for Caregivers

National Lifespan Respite Conference  
September 15, 2022

# Our Mission

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



# Our Founder

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“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

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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

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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](mailto: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





# Working While Caring National Surveys 2021

Elizabeth Harrington, Partner

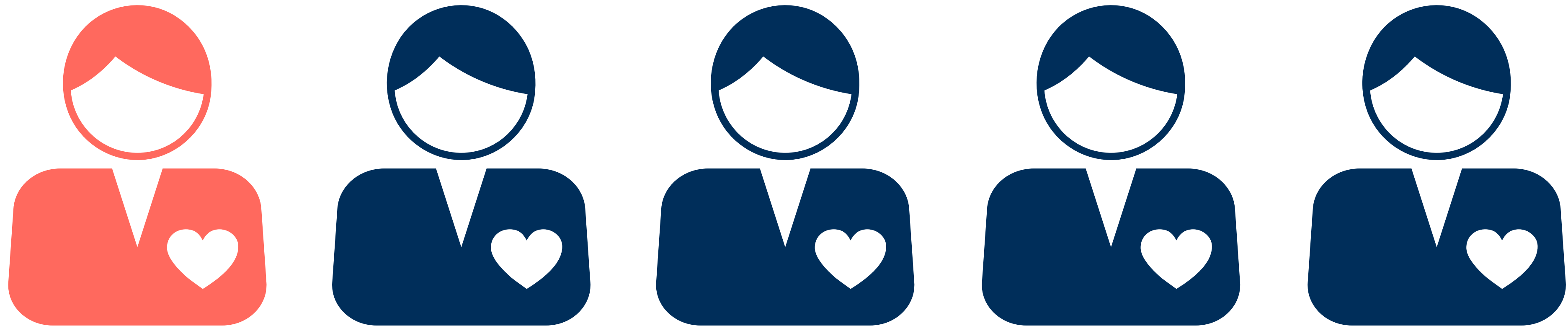
Bill McInturff, Partner



# National Survey Data: Prevalence

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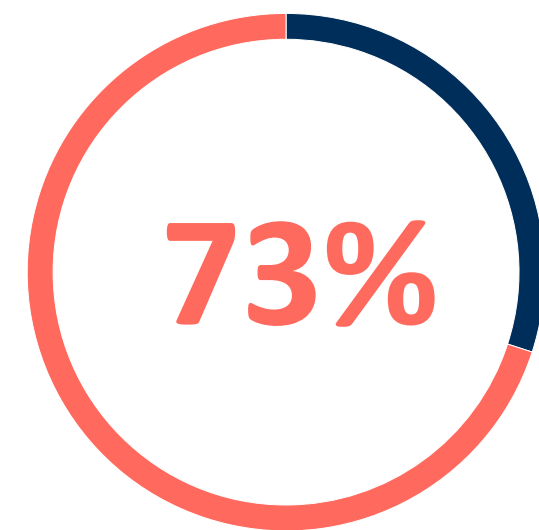
**ONE IN FIVE**



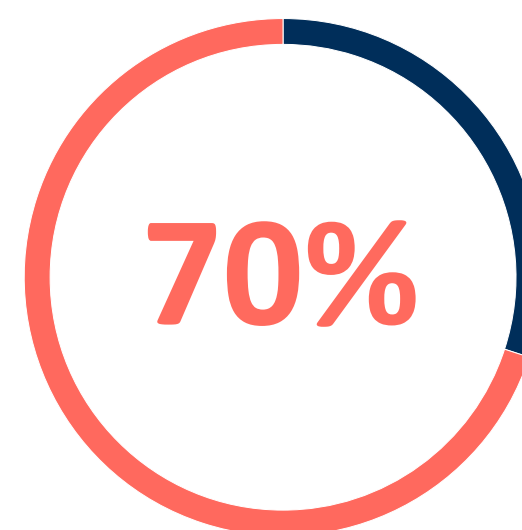
**US workers cares for a family member who is ill, aging, or disabled, and most of these caregiver employees (CEs) are employed in full-time jobs**

# Workplace Effects

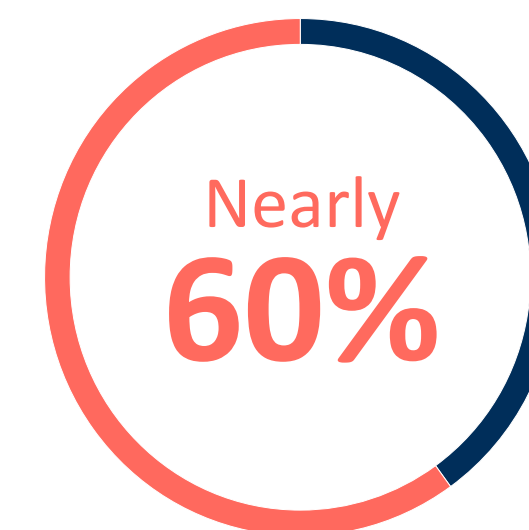
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had to leave work  
early or unexpectedly



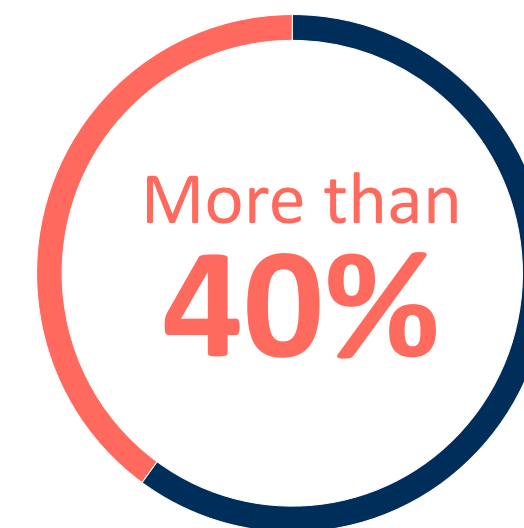
Had to call out  
from work  
for one day



had to take two or more  
days off in a row from work



had to quit a job to  
care for a relative



had to go to  
part-time  
work

## National Caregivers

### Biggest Challenges – Ranked by 1<sup>st</sup> Choice

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



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

# Invisible Overtime

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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

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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

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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

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## 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

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**We have launched a 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

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**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

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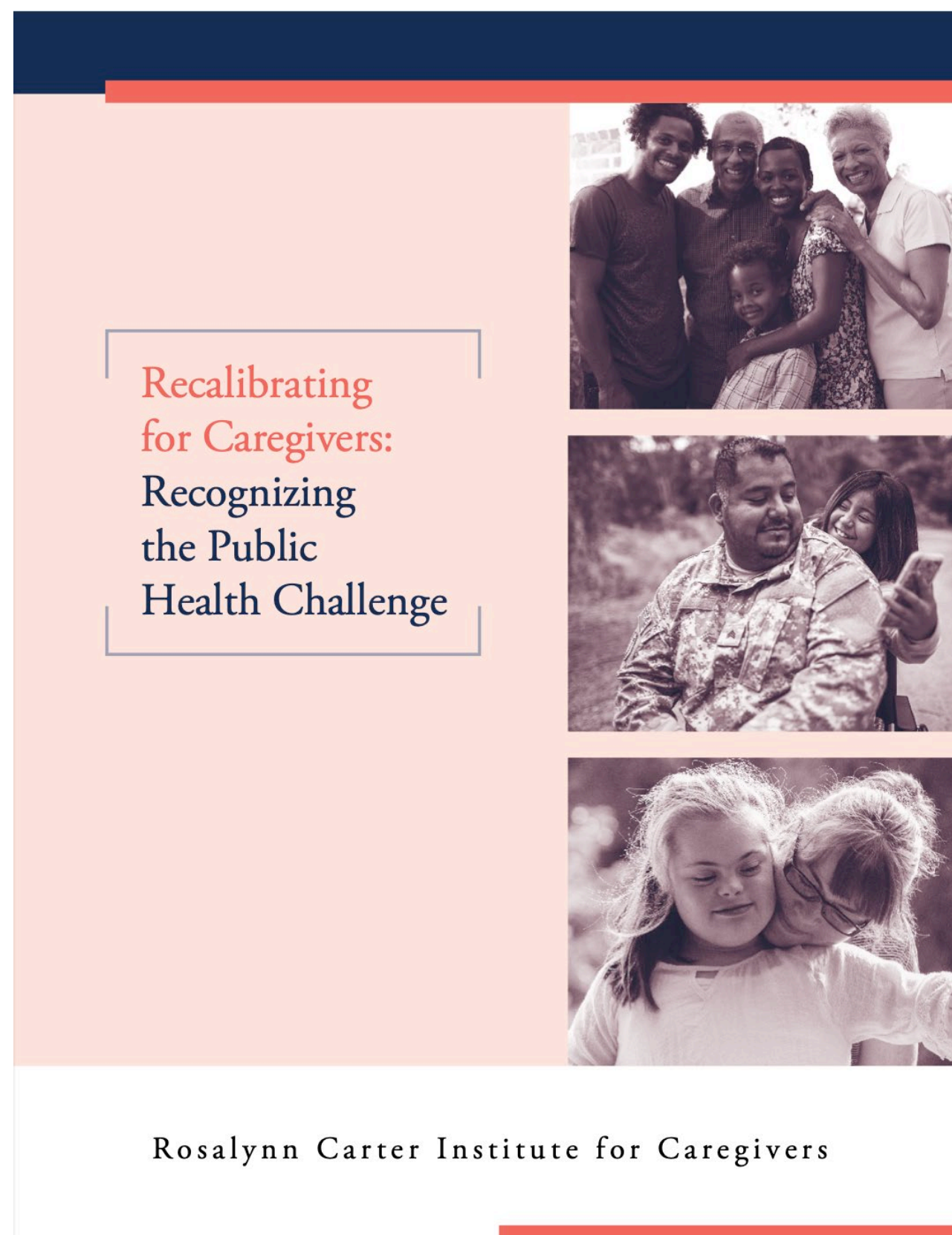
## WE'RE PARTNERING WITH EMPLOYERS

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



Rosalynn Carter Institute for Caregivers

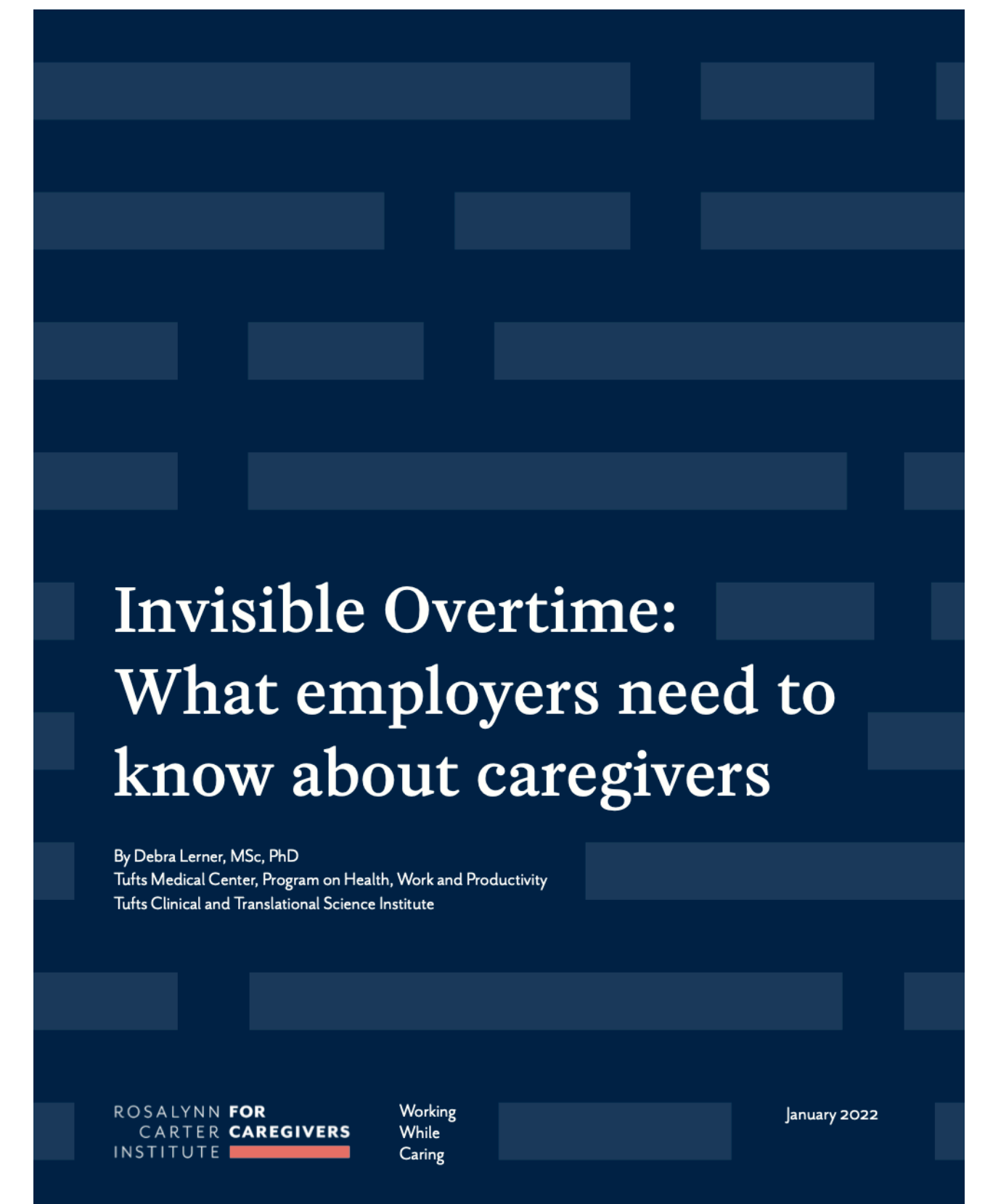


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INSTITUTE

PUBLIC OPINION  
STRATEGIES  
turning questions into answers

*Working While Caring: A National Survey of  
Caregiver Stress in the U.S. Workforce*  
Key Findings  
September 28, 2021

Elizabeth Harrington, Partner  
Bill McInturff, Partner



**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

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January 2022

Thank you

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