Breaking Down Barriers to Caregiving Support

Overview

Caregiving is a near universal human experience. Most of us either are, have been, or will be a caregiver at some point in our lives.

Whether it's for an aging parent, a child with unique needs, a spouse recovering from a procedure, a neighbor navigating a tough diagnosis, or even yourself, family caregiving takes many forms across all phases of life. Often, individuals are taking care of more than one person at once, and doing so while also trying to juggle a full time job.

To meet the needs of today's workforce, a growing number of employers are focused on supporting employees' caregiving needs. However, stigma around caregiving means many caregivers are simply not comfortable speaking up about their care responsibilities or asking for help.

Over the last 3-5 years, we've seen mental health become destigmatized and normalized, particularly in the workplace. This has helped people talk openly about their mental health, and also bring light to the support systems and resources there to help. It begs the question: how can we get caregiving to this same place?

In Fall 2022 EHIR breakout sessions, cohort members discussed their perceptions on the topic of caregiving stigma, the causes and impacts, and strategies employers can use to help build a culture that supports caregivers. This paper dives into the issue of caregiving stigma and shares employer insights from our discussions.

Understanding caregiving stigma

Just 56 percent of working caregivers say that their direct supervisors are aware of their caregiving duties, according to AARP. There are a variety of reasons why family caregivers may choose not to disclose their situation at work, but stigma around caregiving often plays a role.

In one survey, **only 41 percent of respondents agreed that employees at their organizations are comfortable identifying their caregiver status to managers and colleagues** – and just 3 percent strongly agreed. Of the 274 respondents to an open-ended question about barriers to caregiver identification in the workplace, 38 identified stigma and 55 identified fear of being passed over for promotions or projects. Caregivers worry that discussing their caregiving duties will lead to them being perceived as less committed to their team, their work, and their job.

This fear has wide-ranging consequences. Caregivers who are uncomfortable sharing their status often hold out until they are **forced to take an extended leave of absence or step out of the workforce** altogether, either because their loved ones are in a crisis that requires their full attention, or because

they are so burnt out from managing their dual responsibilities that they can no longer handle it. In fact, **32% of all U.S. employees** have left a job at some point in their careers due to caregiving responsibilities.

And because caregivers feel like they can't share their full selves with friends and coworkers, they are **overwhelmingly lonely** – an ironic reality considering how likely it is that the person sitting across from them at work is also caring for someone. This loneliness carries serious risks. **Between 40 and 70 percent of family caregivers experience clinical depression**, and those experiencing isolation are at an increased risk of physical health concerns as well.

Issues of caregiving stigma go hand-in-hand with awareness and self-identification issues: since not enough people are talking about caregiving, many don't realize that the hours they spend helping their loved one constitutes caregiving. In fact, **an estimated 50% of people caring for a loved one don't even identify with the term "caregiver."** They simply see themselves as being a 'good daughter,' a 'good parent,' a 'good spouse,' and feel they are simply doing their family duty — one that they must manage on their own.

These individuals take on the same responsibilities as those who do self-identify as caregivers — and experience the same risks to their wellbeing and ability to stay engaged in the workforce. However, they either aren't aware there's help available for them, don't think it's acceptable to ask for help, or it may not even occur to them to seek support.

Ultimately, caregiving stigma and self-identification issues are a barrier to employees getting the support they need.

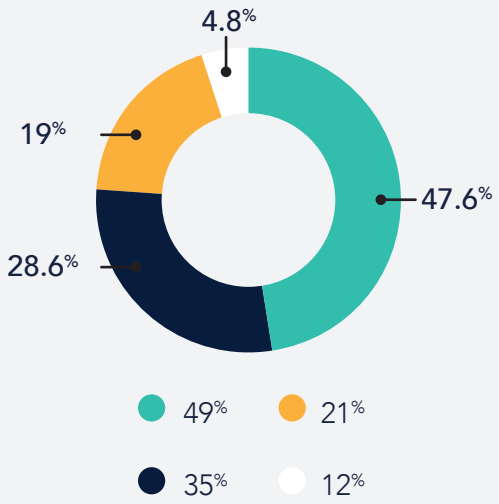
Are we talking about caregiving enough?

As an illustrative example, EHIR member polling showed that the prevalence of mental illness vs. the prevalence of caregiving in the U.S adult population is not commonly known.

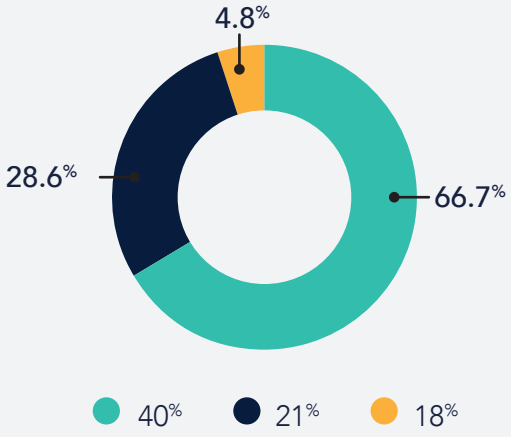
Perhaps surprisingly, the percent of U.S adults caring for an aging, ill, or disabled loved one (**21%**) is the same as those that experience a mental illness each year (**21%**). And when you factor in parenting and other types of informal care situations, it's actually a staggering **73% of working adults** who report having some form of current caregiving responsibility.

The caregiving crisis touches nearly all of us, but it arguably doesn't get nearly the attention that mental health does (not to downplay the importance of mental health awareness and support, which has made strides in recent years).

What percentage of U.S. adults do you think experience mental illness each year?



What percentage of U.S. adults do you think serve as family caregivers?



The more we shed light on the work of unpaid family caregivers, the more employees will start to recognize and embrace themselves in that role. And the more we normalize caregiving, the more likely employees are to get the support they need.

And the more we normalize caregiving, the more likely employees are to get the support they need.

Employer perceptions on caregiving stigma in the workplace

Employer attendees weighed in on whether caregivers face stigma, why they might face stigma, and the current conversation around caregiving in the workplace.

- Benefits leaders for the most part agreed that the pandemic helped open up the conversation around caregiving, which is a good step, but that there is still a lot of work to be done. The question is, 'now what?'
- The presence or degree of stigma around caregiving varies by company or even by team. There is more openness to talk about care concerns in some companies compared to others.
- One real-life example that was shared was about an employee who had been out on maternity leave. She assumed she would not be eligible for a promotion that year, even though it was deserved. She received the promotion and was surprised she got one due to her personal life situation, which illustrates that there is still uncertainty and stigma about how handling your family responsibilities (and taking leave) may impact career growth.
- Employer attendees commented on the gender disparities in caregiving, with one member stating "when men are identified as caregivers it's 'celebrated', but when women are, it's just sort of expected." These gender-based expectations around care contribute to stigma around speaking up and seeking support.
- It was also noted that cultural expectations around caregiving, particularly of elders, can impact how an employee views their role as a caregiver — if they identify with the term, and if they're comfortable speaking up or asking for help.
- A couple attendees stated they have received blowback from non-caregivers, as these employees feel they are unfairly taking up the slack when caregiving employees need to take time off or take leave to attend to care issues. Particularly with childcare, and the feeling that "it was their choice to have kids." Capacity and coverage is an area for employers to thoughtfully consider as the need for caregiving grows, to reduce stigma around care and make sure all members of the team feel supported.
- Each group discussed how employees don't often realize they're a caregiver, even though they are taking on caregiving tasks for someone in their life. Redefining and raising awareness for what caregiving looks like is needed to help break down barriers to caregiving support as well.

Capacity and coverage is an area for employers to thoughtfully consider as the need for caregiving grows, to reduce stigma around care and make sure all members of the team feel supported.

Building a culture of care matters

Employer attendees discussed strategies and solutions to break down the stigmas associated with caregiving. There was resounding agreement that culture matters when it comes to destigmatizing caregiving and providing effective support. Building a culture of care is driven most commonly by leadership, policies, programs, and community.

Here are some of the strategies that benefits leaders are employing today:

Senior leadership modeling and vulnerability

"A culture of caring starts from the top" was a sentiment shared by many cohort participants. One attendee stated that senior leaders telling their caregiving story went a long way to break the stigma at their organization.

A culture of caring starts from the top

On the flip side, another member argued that the experiences of senior leaders are not as relatable to employees, and that front-line or middle managers are the key.

Both senior leaders and managers have a role to play. Support from a manager may look like building trust and showing empathy with their team members, providing flexibility when possible, and supporting that flexibility through open communication.

Policy

Caregiving leave came up in each discussion. In the absence of state or federal paid leave, many employers are expanding their leave programs to address a wider variety of caregiving situations.

Anecdotally, some employers present said they introduced dedicated caregiving leave programs. Others said their caregiving leave is embedded within their existing leave programs, though they could perhaps do more to call this out. There is an opportunity for employers to bring more visibility to the leave options available to caregivers.

Another example shared of how policy has helped is a member employer who eliminated manager discretion in the approval for time away. This type of policy indicates corporate support and eliminates a touchpoint where stigma could impact the caregiver's ability to access support.

One attendee said, "we have good policies around caregiving but sometimes how it plays out in the real world is challenging e.g., reduced commissions,, backfilling for Family LOA creating burdens on other employees."

ERGs

Most participants agreed that ERGs can make a difference in helping normalize caregiving and raising awareness for available supports. Some employers have seen lots of energy around caregiving discussions, particularly in their women's ERGs.

Caregiving employees are seeking out communities for support, and additional ERG examples discussed were a 'Generations ERG,' and an ERG (or Women's ERG subgroup) specifically for those that are caring for a loved one.

Storytelling and testimonials

Most attendees agreed that sharing employee stories and testimonials can help foster conversations about caregiving, show that the employer acknowledges this important aspect of their employees' lives, and can make employees feel safer talking about care at work.

One participant said their company made a splash by introducing paid caregiver leave at the same time they rolled out other caregiver supports — a similar approach to when they rolled out mental health. Their launch campaign included caregiver stories and testimonials from all levels of the company, across multiple channels, but it started with senior leaders.

Education

Caregiving creeps up on many employees — the tasks they're helping a loved one with feel manageable today, but all of a sudden something happens and they're in crisis. Meanwhile some employees are not caregivers yet, but will almost certainly have a need in the future. Yet others assume that caregiving support is only available in medical situations, not realizing that caregiving support is available for things like housing, transportation, financial assistance, etc. Attendees discussed the importance of educating and raising awareness for caregiving support among these populations as a piece of the puzzle as well.

Key takeaways

- Stigma around caregiving can be a barrier to getting employees the support they need to balance caregiving, work, and life.
- Members have seen varying levels of stigma in the workplace, but nearly all agree that a caring company culture is essential to destigmatizing care and helping employees feel safe seeking support.
- Top strategies taken to build a caring culture include senior leadership modeling and vulnerability, policies such as caregiving leave, fostering community through ERGs, employee storytelling and testimonials, and education.

EHIR Member Companies

