Paid Leave Alliance for Dementia Caregivers



Paid Family Leave: An Economic and Racial Equity Perspective

Family caregivers often struggle to be in two places at once: at home providing daily care to their loved ones and at work supporting their employers and co-workers. In fact, 60% of dementia caregivers report working while providing care.

The caregiving crisis triggered by COVID-19 underscores the urgent need for comprehensive paid family leave policies to support vulnerable families during times of crisis and beyond.

Research by UsAgainstAlzheimer's (UsA2) on employed dementia caregivers finds that nearly 60% report that the utilization of paid leave benefits improved their health and emotional well-being as they provided care. However, less than half reported having access to these benefits. And, only one in three employed caregivers report having paid and flexible medical and family leave options to help them balance work and family responsibilities.

Dementia Care Challenges for Economically Vulnerable Communities

Despite its benefits, less than half of employed adult caregivers surveyed reported having access to paid medical and family leave. Slightly less than half (49%) of caregivers surveyed reported that they have access to paid medical and family leave, although this varies significantly among those populations surveyed.

The struggle to provide daily care to loved ones is particularly challenging in communities of color:

60% of caregivers

reported experiencing problems related to financial pressures caused by not being able to work or having to reduce the number of hours they could work during their loved ones' illness. This is especially true for lower wage earners.

Approximately 1 in 4 employed Latino and African American

employed Latino and African American dementia caregivers report that their employers are not providing them the time off they need to care for their loved ones.

The lack of flexibility in the workplace is a challenge for communities of color:

Roughly 5.3% of African Americans have access to flexible days; 7.2% have access to flexible work hours that can be used for caregiving.

Only 11.5% of Latino workers are likely to have access to paid sick days and only 12.4% are likely to have paid vacation.

Caregiving presents critical workforce challenges for communities of color:

46% of African American dementia caregivers reported financial pressures caused by not being able to work due to caregiving.

64% of Latino dementia caregivers

reported financial pressures caused by not being able to work due to caregiving.

According to 2019 Bureau of Labor Statistics data, lower wage earners are less likely to have access to paid leave than higher wage earners and salaried employees. This pressure can be especially devastating to economically challenged families who have higher percentages of unemployment, as well as higher percentages of lower-paying and hourly rather than salaried employment where job protection and more generous benefits are provided.

Only 8% of lower wage earners (\$13.25 per hour) have access to paid leave as opposed to 81% who do not.

17% of the second quartile of wage earners have access to paid leave versus the 88% who do not.

Among the highest wage earners making over \$19.00 per hour, **30%** have access to paid leave versus the 94% who do not.

Without paid leave, vulnerable communities could be left even further behind and generations of wealth, growth, and progress could be wiped out. Paid leave could be a important lifeline for families, especially those in the sandwich generation as they struggle to navigate care and work at a critical time in their lives.

To support this vital segment of the American workforce, policymakers should:



Provide all employed Americans with the right to job-protected leave benefits that pay to care for themselves or their loved ones living with a serious chronic health condition like Alzheimer's and related dementias.



Provide relief for at-home caregivers who have sacrificed income potential to care for their loved ones at home.



Provide meaningful income replacement benefits of a sufficient size and duration to caregivers to enable them to make a real choice about how care is provided.



Provide flexible workplace policies to enable employed caregivers to accompany their loved ones to medical visits including visits related to research.

About the Alliance

The Paid Leave Alliance for Dementia Caregivers, convened by UsAgainstAlzheimer's, is comprised of diverse patient and caregiver advocacy organizations working at the intersections of dementia care, healthy aging, and health equity. The Alliance advocates for access to paid family leave for family caregivers of individuals living with chronic medical conditions such as Alzheimer's and related dementias. To learn more about the Alliance, its principles, and research, please visit https://www.usagainstalzheimers.org/alzheimers-and-paid-leave.