

# Family Caregivers Need to Be Included in the National Conversation on Paid Leave

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## Background on Paid Leave

The Family and Medical Leave Act (FMLA) entitles eligible employees up to 12 weeks of unpaid leave each year to recover from their own serious health conditions or to care for a newborn, a newly adopted child, or a seriously ill family member.<sup>1</sup> FMLA provides important job protections to family caregivers. Unfortunately, up to 40 percent of people in the workforce are not eligible for leave under the existing law and many cannot afford to take unpaid leave.<sup>2</sup>

For good reason, Members of Congress from all parties are now turning their attention to *paid* leave. However, current conversations tend to focus solely on paid leave for new parents, while disregarding the needs of other family caregivers,<sup>3</sup> despite the fact that nearly 70 percent of Americans support paid leave for family caregivers.<sup>4</sup> As defined by the new law, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, a family caregiver is a relative or other individual who has a “significant relationship with,” and who cares for an individual with a “chronic or other health condition, disability, or functional limitation.”<sup>5</sup>

**“UP TO 40 PERCENT OF PEOPLE IN THE WORKFORCE ARE NOT ELIGIBLE FOR LEAVE UNDER FMLA — AND MANY CANNOT AFFORD TO TAKE UNPAID LEAVE.”**

As policymakers consider ways to support working families, any policy involving paid leave should include family caregivers. Here’s why:

### 1. Family caregivers are the backbone of our long-term care system.

- According to the most recent edition of the study, *Caregiving in the U.S. (2015)*, an estimated 43.5 million adults in the U.S provide unpaid care to an adult or a child.<sup>6</sup>
- Even though family caregivers are unpaid, they are the predominant providers of long-term services and supports to persons with illnesses or disabilities.<sup>7</sup>
- Family caregivers spend approximately 24.4 hours a week providing care to their loved ones, with nearly one-quarter providing 41 or more hours of care a week.<sup>8</sup>
- One in three family caregivers has no help at all — paid or unpaid.<sup>9</sup>

### 2. Family caregivers face financial strain and may be forced to choose between work and caregiving because they lack paid leave.

- More than three-quarters of family caregivers incur out-of-pocket costs, and these individuals spend roughly \$7,000 on caregiving per year on average.<sup>10</sup> These costs can significantly add to the stress of balancing caregiving and work.
- The total financial impact of caregiving, including lost wages, lost Social Security benefits, and the impact on pensions, equals \$303,880 for the average male or



female caregiver 50+ who cares for a parent.<sup>11</sup>

- Only 16 percent of civilian workers in the United States have access to paid leave through their employers.<sup>12</sup>
- Six out of 10 family caregivers report having to make a workplace accommodation because of caregiving, such as cutting back on their working hours, taking a leave of absence, receiving a warning about performance or attendance, or other such impacts.<sup>13</sup>
- Family caregivers working at least 30 hours a week are more likely to report having workday interruptions as a result of caregiving.<sup>14</sup>

### 3. Spotlight on California: Paid leave can result in better health outcomes and reduce health system costs.

- California’s paid leave program, the first in the country, went into effect more than 14 years ago.<sup>15</sup> Families in California have experienced positive health benefits, such as faster recovery from illness when being cared for by a family member.<sup>16</sup>

(cont.)

- The implementation of paid leave in California reduced nursing home utilization for older adults by 11 percent.<sup>17</sup>
- The vast majority of California employers report a positive impact on employee profitability, productivity, and performance, or no effect, indicating that the fears some employers expressed when the policy was being considered never materialized.<sup>18</sup>
- In California, labor force participation of family caregivers increased by 8 percent in the short run and 14 percent in the long run. Two groups of people were most affected by paid leave — those who were working and were afforded the ability to better juggle work and caregiving responsibilities; and those who were not working but were enticed to re-enter the workforce once paid leave became available.<sup>19</sup>

## Why Advocates Should Act Now

Family caregivers serve as the backbone of our long-term care system, yet are often forced to choose between their caregiving and work responsibilities. Lack of paid leave can lead to financial strain and negative workplace impacts. Evidence shows that paid leave programs can result in better health

outcomes and lower overall health care system costs.

Recent federal activity on the issue of caregiving as America ages is encouraging. Notably, congressional leadership on the RAISE Family Caregivers Act emphasized the critical importance of supporting family caregivers across the lifespan. Establishing public policies that sustain and support the unpaid caregiving workforce is a critical consideration to supporting population health and strengthening working families.

It is time to build upon this momentum and ensure that caregivers are included in the national conversation on paid leave.

## Further Reading

- **Breaking New Ground: Supporting Employed Family Caregivers with Workplace Leave Policies.** AARP. September 2018.<sup>20</sup>
- **Raising Expectations: A State-by-State Analysis of Laws That Help Working Family Caregivers.** The National Partnership for Women and Families. September 2018.<sup>21</sup>
- **Security and Stability: Paid Family and Medical Leave and its Importance to People with Disabilities and Their Families.** The Arc and the Georgetown Center on Poverty. October 2017.<sup>22</sup>

- **The Importance of Paid Leave for Caregivers: Labor Force Participation Effects of California's Comprehensive Paid Family and Medical Leave.** Center for American Progress. September 2017.<sup>23</sup>

## About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at [www.caregiving.org](http://www.caregiving.org).



<sup>1</sup> The National Partnership for Women and Families. (2018). Family and Medical Leave Act. Retrieved from <http://www.nationalpartnership.org/issues/work-family/fmla.html>

<sup>2</sup> See note 1.

<sup>3</sup> Zietlow, A. (2018, July 17). Where Do Family Caregivers Fit in the Debate Over Paid Family Leave? Institute for Family Studies. Retrieved from <https://ifstudies.org/blog/where-do-family-caregivers-fit-in-the-debate-over-paid-family-leave>

<sup>4</sup> Stepler, R. (2017, March 23). Key Takeaways on Americans' Views of and Experiences with Family and Medical Leave. Pew Research Center. Retrieved from <http://www.pewresearch.org/fact-tank/2017/03/23/key-takeaways-on-americans-views-of-and-experiences-with-family-and-medical-leave/>

<sup>5</sup> RAISE Family Caregivers Act, Pub. L. No. 115-119, 132 Stat. 23. (2018). Retrieved from <https://www.congress.gov/115/plaws/publ119/PLAW-115publ119.pdf>. "Family caregivers" may also be described as "informal" caregivers, carers, careN partners, or caretakers.

<sup>6</sup> The National Alliance for Caregiving and AARP Public Policy Institute. (2015, June). Caregiving in the U.S. Retrieved from [https://www.caregiving.org/wp-content/uploads/2015/05/2015\\_CaregivingintheUS\\_Final-Report-June-4\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf)

<sup>7</sup> Thach, N. & Wiener, J. (2018, May). An Overview of Long-Term Services and Supports and Medicaid. U.S. Dept. of Health and Human Services. Retrieved from <https://aspe.hhs.gov/system/files/pdf/259521/LTSSMedicaid.pdf>

<sup>8</sup> See note 6.

<sup>9</sup> See note 6.

<sup>10</sup> Rainville, C., Skufca, L., & Mehegan, L. (2016, November). Family Caregiving and Out-of-Pocket Costs: 2016 Report. AARP. Retrieved from [https://www.aarp.org/content/dam/aarp/research/surveys\\_statistics/ltc/2016/family-caregiving-costs.doi.10.26419/252Fres.00138.001.pdf](https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/family-caregiving-costs.doi.10.26419/252Fres.00138.001.pdf)

<sup>11</sup> MetLife, the National Alliance for Caregiving, and the Center for Long Term Care Research and Policy, New York Medical College. (2011, June). Caregiving Costs to Working Caregivers. Retrieved from <https://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf>

<sup>12</sup> Bureau of Labor Statistics. (2018, March). Access to Paid Personal Leave. Retrieved from [https://www.bls.gov/ebs/paid\\_personal\\_leave\\_122017.htm](https://www.bls.gov/ebs/paid_personal_leave_122017.htm)

<sup>13</sup> See note 6.

<sup>14</sup> See note 6.

<sup>15</sup> The National Partnership for Women and Families. (2018, July). State Paid Family and Medical Leave Insurance Laws. Retrieved from <http://www.nationalpartnership.org/research-library/work-family/paid-leave/state-paid-family-leave-laws.pdf>

<sup>16</sup> Milkman, R. & Appelbaum, E. (2013). Unfinished Business: Paid Family Leave in California and the Future of U.S. Work-Family Policy. Cornell University ILR School. Retrieved from [https://fhop.ucsf.edu/sites/fhop.ucsf.edu/files/custom\\_download/Unfinished%20Business%20-%20Paid%20Family%20Leave%20in%20CA%20and%20the%20future%20of%20US%20Work-Family%20Policy.pdf](https://fhop.ucsf.edu/sites/fhop.ucsf.edu/files/custom_download/Unfinished%20Business%20-%20Paid%20Family%20Leave%20in%20CA%20and%20the%20future%20of%20US%20Work-Family%20Policy.pdf)

<sup>17</sup> Arora, K. & Wolf, D. (2017, November 3). Does Paid Family Leave Reduce Nursing Home Use? The California Experience. Journal of Policy Analysis and Management, 37(1), pp. 38-62.

<sup>18</sup> The National Partnership for Women and Families. (2018, September). Paid Leave Works in California, New Jersey, and Rhode Island. Retrieved from <http://www.nationalpartnership.org/research-library/work-family/paid-leave/paid-leave-works-in-california-new-jersey-and-rhode-island.pdf>

<sup>19</sup> Saad-Lessler, J. & Bahn, K. (2017, September 27). The Importance of Paid Leave for Caregivers. Center for American Progress. Retrieved from <https://www.americanprogress.org/issues/women/reports/2017/09/27/439684/importance-paid-leave-caregivers/>

<sup>20</sup> Available at: <https://www.aarp.org/content/dam/aarp/ppi/2018/08/breaking-new-ground-supporting-employed-family-caregivers-with-workplace-leave-policies.pdf>

<sup>21</sup> Available at: <https://www.nationalpartnership.org/research-library/work-family/raising-expectations-2018.pdf>

<sup>22</sup> Available at: [https://www.thearc.org/file/public-policy-document/Georgetown\\_FFML-report\\_Dec17.pdf](https://www.thearc.org/file/public-policy-document/Georgetown_FFML-report_Dec17.pdf)

<sup>23</sup> Available at: <https://cdn.americanprogress.org/content/uploads/2017/09/26141822/BahnPaidLeaveLaborForce-report.pdf>