



UsAgainstAlzheimer's



April 26, 2021

The Honorable Joseph Biden Jr.
President of the United States
The White House
1600 Pennsylvania Avenue,
N.W. Washington, DC 20500

The Honorable Kamala D. Harris
Vice President of the United States
The White House
1600 Pennsylvania Avenue,
N.W. Washington, DC 20500

Re: Paid Leave for Family Caregivers Across the Lifespan

Dear President Biden and Vice President Harris:

On behalf of more than 53 million family caregivers in the United States, we applaud the Biden-Harris Administration for promising to ease the financial burdens of care and increase access to long-term services and supports for this critical but underrepresented population. This unpaid workforce, consisting of one in five Americans, underpins our long term services and supports system, helping older adults and people with disabilities or chronic conditions who cannot access long term services and supports to manage their health and wellness.

We write to urge you to prioritize these families when developing additional—and needed—economic recovery policies, including a permanent paid family and medical leave policy that is inclusive of all family caregivers across the lifespan.

Over the past year, millions of family caregivers found themselves needing to isolate or take leave to care for family members, scrambling to fill gaps in care—often without paid leave—as many older adults and people with disabilities lost access to services. Many people are sandwiched between providing care to an older adult or relative with a health condition and typical childcare duties. Children with disabilities relied on family caregivers not only for lost services, but for school demands as well. With the limited exception tax credits to cover a narrow scope of COVID-related leave, federal response legislation to the coronavirus pandemic has largely excluded support for family caregivers.

Unfortunately, the impacts of this omission—as with the pandemic itself—have disproportionately fallen on the shoulders of families of color. Black, Indigenous, and people of color have excessively died and faced negative economic impacts in addition to facing these challenges. A recent survey by the Bipartisan Policy Center found that 16% of Latino and 13% of Black adults have left the workforce to provide care for an adult family member during the pandemic. This essential workforce, consisting largely of women of color that provide frontline services, faced heightened risk of COVID and frequently lacked paid leave despite needing to isolate to protect those they serve. In communities impacted most by health and economic disparities, the pandemic's repercussions could affect the ability to provide care for generations to come.

Although vaccination efforts are ahead of schedule, many families will continue to live in a state of emergency after the pandemic is over. Research from the National Alliance for Caregiving shows that over 50% of family caregivers are dependent on hourly wages for their income, suggesting that unpaid time they take off to provide care further threatens their economic stability. Sixty two percent of caregivers working over 30 hours or more per week say paid leave would help them financially.

According to the most recent Department of Labor commissioned study of the Family and Medical Leave Act, nearly one in five “leaves” taken for family caregiving purposes is to care for an individual not covered under the FMLA's limited definition of “family member.” All nine states (including the District of Columbia) that have enacted paid leave have included provisions that allow leave to care for a more inclusive range of family members that more accurately reflects the lived realities of families. Despite recent expansions of paid leave in states and changes to the federal system, we believe that a national paid leave program is necessary so that families do not need to choose between their jobs and their caregiving responsibilities.

Paid leave is a crucial job support that enables family caregivers to fully participate in the workforce. To truly meet the needs of all working people, a national paid family and medical leave program should meet basic standards that protect and support all types of caregivers, including the following:

- It must provide medical, parental and caregiving leave.
- It must be comprehensive by covering all workers, including part-time workers and self-employed workers, regardless of employer size, regardless of their job or employer, and allow leave for all Family and Medical Leave Act (FMLA) covered events.
- It must include workers receiving Social Security Disability Insurance benefits or Supplemental Security Income benefits.
- It must provide the same amount of leave regardless of a worker's gender.
- It must replace individuals' wages at an adequate level so that people can afford to take time off, as well as a meaningful duration of leave, so that people have enough time to meet their family or medical needs.
- It must guarantee that people can take the time off they need without fear of retribution or having to worry if their job will still be there for them when they return.
- It must be funded affordably and sustainably to not create an undue burden on either employees or employers.
- It must have sufficient administrative resources to not burden the agency from which it is administered and should be created with new funding sources and not be carved out of or borrowed from funds dedicated to Social Security or other crucial federal safety net programs.

- It must be thoughtfully incorporated into the system of federal employment laws that exist today to ensure that no existing protections are limited.
- It must have a broadly inclusive definition of family and must expand the list of those eligible under FMLA to, at a minimum, include siblings, aunts, uncles, cousins, nieces, nephews, grandparents, grandchildren, and domestic partners.

A national policy on paid leave can help alleviate challenges facing working family caregivers who often struggle to be in two places at once: at home providing daily critical care needs to those who rely on them and at work supporting their employees and co-workers and earning an income. Congress, and the Biden-Harris administration can provide a much-needed lifeline to these families as it builds back better.

The undersigned organizations express our support for the creation of a flexible, comprehensive, and inclusive paid leave policy, aligned with the above principles, and stand at the ready to help build our nation's care economy. For more information, contact Mike Wittke at mike@caregiving.org, Stephanie Monroe at smonroe@usagainstalzhaimers.org or Bethany Lilly at lilly@thearc.org.

Sincerely,

AfricanAmericansAgainstAlzheimer's Network
Allies for Independence
Alzheimer's Los Angeles
American Association on Health and Disability
American Geriatrics Society
American Society on Aging
Association of California Caregiver Resource Centers
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Care Generation
Caregivers on the Homefront
Caring Across Generations
Cancer Support Community
Center for Public Representation
Easterseals
Elizabeth Dole Foundation
From The Bottom Up Foundation, Inc
Fund for Community Reparations for Autistic People of Color's Interdependence, Survival, & Empowerment
Greater Wisconsin Agency on Aging Resources, Inc.

Hawaii Family Caregiver Coalition
HFC
Institute for Family Caregiving, Inc.
Justice in Aging
Lake County CaregiverNet
Lakeshore Foundation
Latinos for a Secure Retirement
LatinosAgainstAlzheimer's Network
Lewy Body Dementia Association
Lifespan of Greater Rochester
Medicare Rights Center
National Academy of Elder Law Attorneys
National Alliance for Caregiving
National Association for Home Care & Hospice
National Association of Councils on Developmental Disabilities
National Consumer Voice for Quality Long-Term Care
National Council on Aging
National Council on Independent living
National Disability Institute
National Patient Advocate Foundation
National Respite Coalition
North Carolina Coalition on Aging
Patient Centered Innovation, Inc.
PHI
Retirees Department, APWU AFL-CIO
TASH
The Arc of the United States
The Balm In Gilead, Inc.
The Gerontological Society of America
The Global Foundation for Peroxisomal Disorders
The John A. Hartford Foundation
The North Carolina Serious Illness Coalition
The Youth Movement Against Alzheimer's
Triage Cancer
United Way of Northern New Jersey
UsAgainstAlzheimer's
Women's Institute for a Secure Retirement
Women's Brain Project
World Institute on Disability