

PO Box 647 • Americus, GA 31709

February 5, 2021

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

Dear Mr. President,

Thank you for your swift action and detailed plan for emerging from the COVID-19 pandemic. As the national strategy continues to evolve and take shape, we are writing to advocate for unpaid family caregivers.

First, please consider formally engaging leaders in the caregiving community to represent the more than 53 million Americans who serve as unpaid family caregivers. As you know from personal experience, caregivers are essential to assuring quality care, reducing health care costs, and helping the most at-risk Americans to be safe, stay informed, and ultimately get vaccinated.

Caregivers are the invisible frontline of our health care system. Overlooking or underestimating the critical role that they play will be detrimental to the national COVID strategy and to the health, well-being, and economic security of our nation.

Second, as you know, our founder, former First Lady Rosalynn Carter, believes that effective policy must be intentional about and responsive to the needs of caregivers. Caregiving should be an issue addressed through a public health lens and the impacts of caregiving should be considered along with other social determinants of health.

As you continue to shape and implement this strategy, please consider the following recommendations:

Combating Inequities. The COVID-19 Health Equity Task Force has an extraordinary task in addressing systemic health and social inequities that have been magnified by the pandemic. In addition to eliminating barriers to vaccination in communities hit hardest by the virus, we urge the administration to consider the additional burdens on caregivers who must take leave from work or spend uncompensated time to secure COVID tests and/or vaccinations for themselves and their loved one. Caregiving status is itself a social determinant of health that exacerbates many systemic inequities, and we encourage the administration to include caregivers when it outlines those most at-risk for COVID-19.

Collecting Caregiver Data. Caregivers have a front-row seat to their care recipient's experience, and this proximity allows for valuable insights that, to date, largely have been lost to history. As the government expands the data infrastructure to track vaccine distribution and monitor safety and efficacy, caregivers should be included. The future of the nation's pandemic and other emergency preparedness relies on the ability to harness a caregiver's unique position and proximity to a vulnerable patient.

Caregivers can provide information on adverse effects from the vaccine, be a quick check on efficacy, and improve compliance for a second dose. For the same reason, caregivers should be targeted for clinical trials, as their presence may improve compliance and response rates. Involving caregivers also can facilitate the increased testing called for in the strategy by ensuring their care recipient receives a test. Caregivers can be a critical resource in expediting contact tracing, as well.

Further, caregivers themselves are a vulnerable population, and they face stressors and burdens that make them more at-risk. Studies have shown that whether someone is a caregiver can have a [dramatic influence on their health and well-being](#). Collecting data from caregivers during this pandemic can yield information that will have long-lasting effects, informing policies and programs for those who provide care to people suffering from many other diseases and chronic conditions.

Catching Caregivers in Social Safety Nets. As the administration considers eligibility and enrollment flexibilities for select programs during the pandemic, we encourage leaders to consider the inequitable burdens borne by caregivers during this pandemic, whether they are providing care to someone suffering from an acute COVID infection, lasting symptoms of the disease (long [COVID](#)), an injury due to military service, or a slow degenerative disease. Caregiving responsibilities can have a [detrimental financial impact](#) for employed caregivers. Sixty percent report that their caregiving has required them to cut back their hours, take a leave of absence, or has had an otherwise punitive impact. Including caregivers in paid leave policies, including emergency paid leave, would be a meaningful statement.

Safely Opening Adult Care Facilities. We commend the administration's goal of safely opening schools, businesses, and travel to bolster the economy. Adult day facilities and home health agencies should be included alongside childcare centers and at-home providers. Adult day services provide care to adults with dementia, substance issues, and physical disabilities, and home health agencies offer in-home care. Both adult day services and home health agencies support patients and their caregivers, who benefit from a time of respite. These facilities have suffered economically during the pandemic as their clients must make impossible decisions about their loved one's safety. Like childcare facilities, the continuity of these services will have long-term repercussions on the economy.

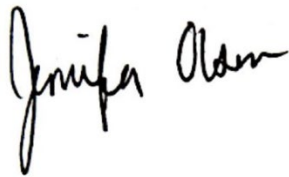
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Engaging Caregivers. The pandemic response will succeed or fail depending on buy-in from the American populace, including those who have been infected by or are at high risk for contracting COVID-19. Engaging family caregivers in our national strategy will benefit the entire system. Caregivers provide a direct connection to the most hard-to-reach and at-risk populations, particularly those who are older or who suffer from chronic disease or cognitive impairment. The federal response will benefit from soliciting input from caregivers to help guide its response and outreach.

On behalf of America's 53 million caregivers – and the many more who start their caregiving journey each day – we thank you for recognizing and appreciating this invisible frontline of our nation's health care system.

Sincerely,



Jennifer Olsen, DrPH
Chief Executive Officer

cc: Mrs. Rosalynn Carter
First Lady Dr. Jill Biden
The Honorable Vice President Kamala Harris
Xavier Becerra, Secretary-designate, Department of Health and Human Services