



November 16, 2020

President-Elect Biden Transition Team
COVID-19 Advisory Board
Biden for President
P.O. 58174
Philadelphia, PA 19102

Dear Biden-Harris COVID-19 Advisory Board,

Thank you for your steadfast leadership during this unprecedented public health crisis.

Located in Georgia, the Rosalynn Carter Institute (RCI) advocates for more than 53 million unpaid family caregivers across America. As Executive Director, I respectfully write to urge you to consider the health, well-being, and financial security of caregivers as you work with the President-elect to outline a comprehensive strategy to beat COVID-19.

My training and previous career was as an epidemiologist, and I spent years engaging communities on how best to report and respond to emerging health threats. The importance of listening to experts across government, science, and medicine as we continue to navigate our COVID-19 response cannot be overstated. Since coming to RCI, I have learned about the need to include the voice of family caregivers as well, as they are the invisible frontline of our health care system. Our founder, former First Lady Rosalynn Carter, continues to remind me how isolating and stressful aspects of caregiving can be, particularly given the uncertainty that plagues this time. Caregivers and their loved ones are both vulnerable to this virus and to the challenges that result, and they inform our response.

The pandemic has only compounded existing challenges for this population, cutting off caregivers from traditional supports and sources of respite and increasing disparities across income, race, and geography. As Dr. Biden knows from our work with veteran and military caregivers in our Operation Family Caregiver program, RCI has long recognized emerging caregiver constituencies such as those with service members wounded during the Global War on Terrorism. Many new caregivers will emerge in the United States as a result of the COVID-19 pandemic, and many of them will be people of color since racial and ethnic minority populations have been disproportionately affected. If the racial reckoning that has taken place this summer has taught us anything, it is that we cannot wait to begin this work; we must start now.

While there is no typical caregiver, nor a typical list of caregiving tasks, there are clear ways where unpaid, informal caregivers intersect with our nation's public health system, as well as impact our COVID response. Family caregivers often serve as the healthcare scaffolding in their households, and their role in reducing demand on emergency room services, their role in providing details to contact tracers, and their role identifying early symptoms and advocating for a COVID test for their care recipient should not be overlooked. Caregivers are key in strengthening our response infrastructure, and supporting our health system's recovery.

*“There are only four kinds of people in the world:
those who have been caregivers, those who are currently caregivers,
those who will be caregivers, and those who will need caregivers.” — Rosalynn Carter*



RCI is encouraged and excited about President-elect Biden's commitment to the plight of the caregiver. Our newest paper, [*Recalibrating for Caregivers: Recognizing the Public Health Challenge*](#), analyzes shifting demographics, economic impact, and caregiver physical and mental health data, and calls for better understanding of how caregiving status affects health and well-being. Our survey completed in the Fall of more than 400 caregivers across 46 states also showed that a vast majority caregivers – 83 percent – experienced increased stress since the start of the pandemic. While there are long-term, systemic changes needed to help caregivers, including breaking down siloes across health care, government, and business to create a more supportive infrastructure, we have urgent COVID-19 related needs that I hope you will consider in your recommendations:

- **Study the long-term effect on caregivers caring for loved ones recovering from COVID-19.** We applaud the \$290M funding increase for the NIH's National Heart, Lung, and Blood Institute included in the HEALS Act. The Institute is conducting an important longitudinal study around the effects of COVID-19 exposure with their RED and BLUE CORAL studies. This unique and in-depth look at the impact of COVID-19 could be expanded to assess the long-term impacts on family caregivers. Given the potential decades-long support that caregivers provide, it would be a missed opportunity not to think about ways to maximize this research investment. The learnings from caregivers and care recipients recovering from COVID-19 (especially those who spent time in an ICU) could inform dementia caregiver and TBI caregiver support, as the cognitive test scores have been shown to be similar.
- **Expand emergency paid family leave beyond childcare to include eldercare.** Emergency legislation provides 10 days of paid sick and 10 weeks of paid family caregiving, but most caregivers do not qualify. The sick leave reaches as few as 25% of workers but has proven in the current form to reduce COVID cases by 400 per day in each state. Moreover, the family caregiving program only covers parents with school-aged children home due to closures. It misses the tens of millions of working Americans who also care for adult or aging family member at home, an issue amplified by pandemic challenges within facility-based care. These caregivers are navigating lost access to respite care, adult day care, and home healthcare workers. We must expand emergency paid leave and ensure sick leave and family caregiver leave reach everyone.
- **Extend and expand telehealth options.** Home is a new hospital, and unpaid family caregivers are on the frontline, providing more and more care. Telehealth has proven essential to caregivers and their care recipients by reducing the need to leave home for non-urgent care and improving their ability to participate in medical visits and ensure proper follow-up. Moreover, research has shown that caregivers prioritize the health of their care recipient and neglect their own. Telehealth has helped the caregivers prioritize their personal physical and mental health care while still being present for those who rely on them. As you know, higher levels of stress, anxiety, depression, and other mental health effects are common among family caregivers. Please protect and extend telehealth, include caregivers in telehealth conversations, and increase funding for mental and behavioral health interventions.
- **Extend stimulus check financial support to dependents of all ages.** Research has shown that more than three quarters of caregivers incur significant out-of-pocket costs – averaging roughly \$7,000 per year – because of caregiving. The first stimulus checks only included resources for child dependents, but millions have adult dependents who also need resources. There is bipartisan and bicameral support to sending stimulus checks to Americans with adult dependents.

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- **Continue interventions for food security.** Food insecurity is on the rise. Older Americans rely upon food assistance and are less likely to be able to order groceries online, yet containing the virus relies on the ability of people to shelter at home. There has been tremendous focus on student food security interventions, but elder and rural community interventions should also be a top priority.

Thank you again for your tireless work on behalf of all Americans as we continue to fight this pandemic, and for your consideration of these ideas to increase unpaid family caregiver supports. If I can be of any help to you and your staff, please do not hesitate to call (202) 431-0646 or email Jennifer.Olsen@rosalynncarter.org.

Respectfully,

A handwritten signature in black ink that reads "Jennifer Olsen".

Jennifer Olsen, DrPH
Executive Director

cc: Mrs. Rosalynn Carter

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