National Alliance for Caregiving

From the President's Desk
National Alliance for Caregiving
1730 Rhode Island Ave., Suite 812
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VIA ELECTRONIC DELIVERY

April 19, 2021

The Honorable Joseph R. 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: The American Jobs Plan: Building the Family Caregiver Support Infrastructure

Dear President Biden and Vice President Harris:

We at the National Alliance for Caregiving (NAC) applaud the Biden-Harris Administration for promising to ease the financial burdens of care and also increase access to long-term services and supports for the more than 53 million[1] unpaid friend and family caregivers. This unpaid workforce, representing one in five Americans, forms the backbone of our long-term care system, as it is family and families of choice, who help older adults and people with disabilities or serious health care needs to manage their health and wellness.

Mr. President, your compassionate messages to the country describing your experience caring for your son Beau, as well as Dr. Jill Biden's efforts to recognize the needs of those who care for Veterans and wounded warriors have been inspiring and galvanizing to the community.

At NAC, we've worked for more than 25 years to document the lived experience of caregivers through nationally representative data, advocacy, and innovation initiatives. Stories like yours elevate the millions of other family

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[1] National Alliance for Caregiving and AARP. (2020). Caregiving in the United States 2020. Available at https://www.caregiving.org/caregiving-in-the-us-2020/ and https://www.aarp.org/ppi/info-2020/caregiving-in-the-unitedstates.html.

members or close friends who share the experience of being at the side of those who rely on them to cope with serious and often unforeseen health conditions or life altering disability.

We know that the COVID-19 pandemic has amplified the challenges and the national awareness surrounding issues that family caregivers face today as well as prior to the pandemic. Over the course of the public health emergency, we have watched family caregivers fill gaps in care (e.g., assistance with activities of daily living, transportation, medication management and even complex medical nursing tasks) with less access to supports and services,[2] including the loss of child and adult day care services that enable them to work. Others have lost income as a result of economic uncertainty created by this pandemic. In communities impacted most by health and economic disparities, the pandemic's repercussions could affect the ability to provide care for generations to come.

The Biden-Harris Administration's commitment to a comprehensive national strategy for COVID-19 response driven by science, data, and public health, has given Americans a chance to more clearly envision life beyond the pandemic. Although vaccination efforts are ahead of schedule, many families will continue to live in a state of emergency.

The recently released American Jobs Plan has gone a long way to recognize this population and their critical contribution to society by stating that "families feel the financial burden of caring for aging relatives and family members with disabilities." This plan is encouraging and correctly draws to policy solutions that will improve the infrusctructure of wage-earning cargivers.

Yet please do not forget that the challenges facing the unpaid portion of this workforce – sometimes referred to as informal or family caregivers – are quite unique. On behalf of our nationwide community of caregiving partners and advocates, we call attention to the need for a robust national strategy that expands the support infrastructure to address family caregiving as a public health and economic security issue across the lifespan[3][4].

About NAC

NAC's mission is to build partnerships in research, advocacy, and innovation to make life better for family caregivers. Our work aims to support a society which values, supports, and empowers family caregivers to thrive at home, work, and life. As a 501(c)(3) charitable non-profit organization based in Washington, D.C., we represent a coalition of more than 60 non-profit, corporate, and academic organizations; nearly 40 family support researchers with expertise in pediatric to adult care to geriatric care; and more than 50 state and local advocates who support caregivers across the United States. On the international stage, NAC leads and participates in a number of global meetings on caregiving and long-term care. NAC founded the International Alliance of Carer Organizations (IACO), a global coalition that includes 16 non-governmental organizations, and continues to engage with global partners through

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[2] Rosalynn Carter Institute for Caregiving, October 2020. Available at https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-ReportOctober-2020-10-22-20.pdf

[3] National Alliance for Caregivng, Advocacy Collaborative, available at https://www.caregiving.org/advocacy/grassroots-advocacy/

[4] National Alliance for Caregiving, NAC Membership, available at https://www.caregiving.org/our-members/

multinational initiatives like Embracing Carers and in partnership with groups such as Eurocarers and the World Dementia Council.

In this letter, please find information on the following topics, which form the foundation of NAC's policy priorities:[5]

- I. **Expand Caregiver Access to Supports and Services**
- II. **Invest in Caregiver Research and Evidence-Informed Practices**
- III. **Protect the Financial Security of Caregivers**
- IV. **Include Caregivers as a Vital Member of the Health and Human Services System**
- V. **Enhance the Health and Wellness of Caregiver**

I. Expand Access to Supports and Services

Family caregivers cross racial, ethnic, and socioeconomic backgrounds and require a support infrastructure that reaches those in rural and urban settings, as well as those spanning several generations. One of the biggest challenges facing family caregivers is coordinating care across siloed systems of support. According to data from NAC and AARP, a third (31 percent) of caregivers of adults in 2019 reported it was "very difficult" or "somewhat difficult" to coordinate care."

A comprehensive national strategy is needed to not only identify, but also help implement the actions that government, providers, communities and other stakeholders should take to support family caregivers and make it easier for them to navigate health and social systems of care. A robust strategy to support America's caregivers must take into consideration the best plan of action to not only reach caregivers of older adults but also those facing long-term care needs as a result of all serious conditions or disabilities. In addition to caregivers of those with Alzheimer's disease or a related dementia and people with intellectual or developmental disabilities, the national strategy should explicitly address those caring for individuals with serious illnesses, rare diseases, and those managing physical or cognitive impairment at any age.

The RAISE Family Caregiver Advisory Council, authorized under federal law in January 2018,[6] convened in August 2019 and is currently at work,[7] developing a national caregiving strategy before its scheduled sunset in January 2022. However, the need to address the challenges facing America's family caregivers as our population ages, as fewer caregivers are available and as our health care system transitions to a more person and family-centered model will only increase and evolve with time. Coordinating support infrastructure for family caregivers across the lifespan requires ongoing focus. Likewise, ongoing alignment with existing Advisory Committees working on related issues,

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[5] National Alliance for Caregiving, NAC Core Advocacy Principles, available at https://www.caregiving.org/advocacy/.

[6] Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017, P.L. 115–119, 132 Stat. 23 (2018) (as amended by Pub. L. 116–131, title I, §122(b), (c), 134 Stat. 248 (2020)).

[7] Administration for Community Living and RAISE Family Caregiving Advisory Council, "RAISE Family Caregivers Act: Progress Toward a National Strategy to Support Family Caregivers," April 2020. Available at https://acl.gov/sites/default/files/RAISE_SGRG/RAISE%20Family%20Caregiver%20Act_Progress%20Report_23%20April%202020.pdf.

notably the National Alzheimer's Project Act (NAPA) Advisory Council on Alzheimer's Research, Care, and Services and the U.S. Department of Veterans Affairs' Veterans' Family, Caregiver, and Survivor Advisory Committee is needed.

We call for language in the Biden Caregiving and Infrustructure Plans that includes asking Congress to provide federal funding to continue the work of the RAISE Family Caregiving Advisory Council that will allow for implementation of the National Caregiving Stragtegy.

II. Invest in Caregiver Research and Evidence-Informed Practices

Processes to measure progress of a national caregiver infrastructure is also needed for standardized collection and dissemination of information about caregivers across the lifespan and their experiences. It is vital that family caregivers of all backgrounds are engaged stakeholders in a national research and data gathering infrastructure that documents their experiences. Research from NAC and AARP[8] is derived from one of the few caregiving datasets with nationally representative data of African American, Asian American and Pacific Islander and Hispanic. More inclusive, transparent, and representative data is crucial to help remedy existing disparities and ensure more equitable delivery of health care and social supports and meaningful patient and family engagement.[9]

In alignment with recommendations included in the RAISE Family Caregiving Advisory Council's initial recommendations,[10] as well as formal caregiving strategies adopted by several states,[11] a health and human services system that adequately sustains caregivers in promoting public health must invest in evidence-informed caregiver research. To facilitate the development and delivery of programs that support caregivers and their care recipients, ongoing research and data is needed in the following areas:

- Family caregiver service and support utilization
- Potential cost-savings from caregiver interventions
- Demonstration of improved health outcomes for family caregivers
- Increased understanding of the public health implications related to caregiving activities

We call for the language in the Biden Caregiving and Infrastructure Plans that addresses the need for federal agencies such as the FDA, CDC and NIH to do more robust research and data collection analyzing services that are provided to caregivers to ensure data is representative of our diverse population and ensure services are person-and family centered.

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[8] See note 1.

[9] See C. Grace Whiting, No More "One Size Fits All" Research, June 29, 2020. Available at https://www.caregiving.org/no-more-one-size-fits-all-research/.

[10] Administration for Community Living, Family Caregiving Advisory Council Final Recommendations, Nov. 18, 2020. Available at https://acl.gov/sites/default/files/RAISE_SGRG/RAISE%20RECOMMENDATIONS%20FINAL%20WEB.pdf.

[11] See National Alliance for Caregiving, From Momentum to Movement: Developing a Unified Strategy to Support Family Caregivers Across the Lifespan, Feb. 2021. Available at https://www.caregiving.org/wp-content/uploads/2021/02/NAC_50state-Strategy_Report_NAC-FINAL_02_2021.pdf.

III. Protect the Financial Security of Caregivers

As the Biden-Harris Administration has acknowledged, caregiving can have substantial financial consequences for the individual providing care. The economic effects of family caregiving can result in financial strain with substantial short- and long-term financial consequences across demographic groups. Data from AARP shows that 78 percent of caregivers incur out-of-pocket expenses related to caregiving.[12] Family caregivers may cover these out-of-pocket expenses, which averages $7,000 to $9,000 per year, by incurring more debt or diminishing or exhausting short- or long-term savings.

At the same time, caregiving may impact their capacity to work, potentially resulting in lost income and lost credit toward Social Security retirement benefits. About half of caregivers have experienced at least one financial impact as a result of caregiving and over one-third of caregivers have two or more financial impacts, such as stopping or exhausting short- or long-term savings or taking on more debt. When caregivers experience work-related impacts, they more often face financial impacts and are twice as likely to report high financial strain (35 percent). Our research shows that while the majority of caregivers are employed, working caregivers face challenges such as coming into work late or leaving early, reducing their hours, or potentially leaving the workforce altogether. We also know that the majority of working caregivers are living off of hourly wages. We applaud the Biden-Harris Administration for recognizing the need for Social Security credits and tax credits for caregivers. However, the need for workplace and wage protections is crutial for the financial security of family caregivers.

We call on the Biden Caregiver and Infrustructure Plans to include language recognizing the need for paid family leave to ensure those who take time off of work to care for someone with a serious health condition are not excluded from a national policy on paid family and medical leave.

IV. Include Caregivers as a Vital Member of the Health and Human Services System

Caregivers most commonly want information about keeping their recipient safe at home, managing their own stress and help figuring out forms, paperwork, and eligibility for service. Fewer than 3 in 10 say a health care provider, such as a doctor, nurse, or social worker, has asked about what was needed to provide care and just 13 percent say a health care provider has asked what they need to care for themselves. By creating the National Family Caregiver Support Program (NFCSP), Congress explicitly recognized the important role that family caregivers occupy in our nation's long-term services and supports system. However, only about 700,000 caregivers in FY 2014 (the most recent year for which service data is available) received services through the NFCSP. Although this is a very small fraction of the caregivers in need of support, these services helped them to better manage caregiving responsibilities while ensuring their loved ones remained in the community for as long as possible. According the data collected by the Admistration for Community Living, 74 percent of caregivers of program clients report that services enabled them to provide care longer than would have been possible otherwise, 88 percent of caregivers reported that services

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[12] Rainville, Chuck, et al. Family Caregivers Cost Survey: What They Spend & What They Sacrifice: Family Caregiving and Out-of-Pocket Costs: 2016 Report. AARP. November 2016. Available at: https://www.aarp.org/content/ dam/aarp/research/surveys_statistics/ltc/2016/ family-caregiving-costs.doi.10.26419- 2Fres.00138.001.pdf.

helped them to be a better caregiver; and nearly 62 percent of caregivers indicated that without the services they received, the care recipient would be living in a nursing home.

We applaud that President Biden's plan will expand access to home and community-based services (HCBS) and extend the longstanding Money Follows the Person program. However, services offered through HCBS Waivers has always been "optional," not "mandatory," which means that states are allowed to put limits on how many services they offer, who can get the services, and what kind of services are available. The effect has been a long waiting list for community-based services in many states and many other barriers to people getting the supports they need to live and participate in the community.

We call for language in the Biden Caregiving and Infrastructure Plans to ask Congress to make the additional $145,000,000 provided to the National Family Caregiver Support Program in the American Rescue Plan as permanent funding so that states are more equipped to assess the needs of caregivers across all health and home and community-based service entry-points and enable family-centered care coordination and service delivery.

We also call for language in the Biden Insfrustructure Plan asking Congress to make HCBS a mandatory service under Medicaid along with an expansion of "consumer-directed care" (sometimes referred to "self-directed services" and "participant direction") to be available through HCBS Medicaid waivers.

V. Enhance the Health and Wellness of Caregivers

Our data shows that caregiver self-rated health has declined during the past five years. We also know that nearly 4 in 10 caregivers feel having respite services (where someone provided care to the recipient to give the caregiver a break) would be helpful. Unfortunately, only 14 percent of caregivers report having used respite services. In addition to critical medical and nursing tasks and ADL's, caregivers also are performing instrumental activites of daily living (IADL's) such as providing transportation, grocery or other shopping, housework, and preparing meals. Some of these non-medical tasks can be performed by trained volunteers as another form of respite, allowing family caregivers to focus on their own health and wellness and balancing and managing work and family responsibities.

Considering there are critical shortages in the direct care workforce as the number of older adults and persons with disabilities needing assistance continues to grow, volunteers can be an important resource in communities to assist family caregivers, older adults and persons with disabilities needing assistance. With proper training and support, volunteers can provide assistance such as respite and other non-medical forms of assistance. Not only can their presence offset some of the effects of a limited workforce, volunteering can have important benefits for both the volunteers and the people they are assisting. We applaud the references in the Biden Caregiving Plan that encourage the expansion of respite services. By expanding the types of services caregiving offered in the support infrastructure, more respite providers will be available to step in allowing the family caregiver to avoid burnout.

We call for the Biden Caregiving and Infrastructure Plans to ask Congress to expand funding for the National Community Care Corps so that more types of respite services are available and family caregivers are able to prevent further health deteriorization.

Thank you for your time and attention recognizing these crititcal issues that nearly everyone in our country will likely face at some point with very little preparation.

As a community dedicated to providing a voice for family caregivers, we stand at the ready to support the Administration's immediate and longer term efforts to protect the nation's families. Should you have any questions about this letter, please contact me at my information below.

Respectfully,

C Grace Whiting

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Enclosures:
Caregiving in the U.S. 2020 | The National Alliance for Caregiving (One-Pager)
Caregiving in the U.S. 2020 – NAC/AARP Research Report (Full Report)