

VIA ELECTRONIC DELIVERY

June 13, 2023

President Joseph R. Biden Jr. The White House 1600 Pennsylvania Avenue, N.W. Washington, DC 20500

RE: Act On RAISE: Implementing the National Strategy to Support Family Caregivers

Dear Mr. President:

On behalf of the National Alliance for Caregiving (NAC), and the below members of the <u>Act On RAISE campaign</u>, we are writing to express gratitude for the time given from members of your administration, including Secretary Beccera, Under Secretary Elnahal, Acting Administrator and Acting Assistant Secretary for Aging Barkoff, representatives from the Administration for Community Living, and representatives from the Domestic Policy Council to the campaign's steering committee. During our meeting on May 10, 2023, we were given the opportunity to discuss the state of caregiving in the U.S. and the goal of our newly launched campaign – which is to ensure that the implementation of the <u>National Strategy</u> to <u>Support Family Caregivers (National Strategy)</u> results in meaningful improvements in the lives of America's more than 53 million¹ friend and family caregivers.

The Act On RAISE campaign is driven by a broad coalition of partners representing caregiving, aging, disability, and patient advocacy communities. The National Strategy provides a roadmap that highlights our common interests and, if put into action, will over time address many of the challenges faced by unpaid family caregivers. This is why we are focused on accelerating implementation of the National Strategy and strengthening federal leadership in support of family caregivers who contribute \$600 billion annually² in unpaid care to their loved ones, more than all out-of-pocket spending on healthcare in the U.S. in 2021.

We applaud your leadership on family caregiving, including signing <u>recent executive actions</u> aimed at strengthening our care infrastructure – and allocating \$20 million in grants through the U.S Department of Health and Human Services (HHS) to begin implementation of the National

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

² Reinhard, Susan C., Selena Caldera, Ari Houser, and Rita B. Choula. *Valuing the Invaluable 2023 Update: Strengthening Supports for Family Caregivers*. Washington, DC: AARP Public Policy Institute. March 8, 2023. https://doi.org/10.26419/ppi.00082.006

Strategy. These are critical first steps towards bringing the National Strategy to life. We appreciate the Biden-Harris Administration for shining a spotlight on the value of these vital members of our society.

We thank you for your compassionate messages to the country describing your experience as a caregiver, as well as Dr. Jill Biden's efforts to recognize this community. Stories like yours, along with millions of others, demonstrate that caregiving truly connects us all.

We ask for your continued championship of unpaid family caregivers by taking the actions outlined in this letter to drive implementation of the Nation Strategy to Support Family Caregivers:

- I. Accelerate Implementation of the 350 Federal Actions within the National Strategy
- II. Strengthen Federal Level Coordination to Update and Improve the National Strategy
- III. Highlight the Far-Reaching Impacts of Caregiving on Families, Communities, and the Economy Across Sectors.

Accelerate Implementation of the 350 Federal Actions within the National Strategy

Our Ask: Help provide oversight and accelerate implementation of National Strategy federal actions with the potential for highest impact, address gaps, and strengthen actions where needed through administrative authority.

Benchmark for Success: High-impact actions across all appropriate federal agencies are prioritized by agency leadership, implemented expeditiously, and the impact of those actions is communicated to the public.

Rationale: The passage of the RAISE Family Caregivers Act marked a critical milestone in our country's recognition of the need to support family caregivers. The law set in motion an unprecedented and whole-of-society approach to begin to build a national infrastructure that ensures family caregivers have the resources they need to maintain their own health, well-being, and financial security while providing crucial support for others. The National Strategy represents the first time a broad cross-section of the federal government has collaborated with the private sector on a response to the longstanding national need for a comprehensive system of family caregiver support. Although the RAISE Family Caregivers Act did not provide resources or extend congressional authorities to allow for actions within the National Strategy to be implemented upon completion, over 15 federal agencies have identified nearly 350 actions the federal government will take under existing authority in the coming three years that are aligned with and support the vision of the National Strategy.

Please work with appropriate federal agencies to ensure that these actions are implemented on a timely basis. We request that you encourage HHS to invite those federal agencies which have made commitments regarding National Strategy implementation to participate in upcoming RAISE Family Caregiver Advisory Council public meetings so they can report on their progress and engage directly in dialogue with RAISE Advisory Council members around actions taken and any anticipated next steps. Additionally, please request that those agencies which have identified actions in the National Strategy be given an opportunity to provide a publicly available written report on the status of those actions to relevant HHS and White House leadership. The public must hear directly on an ongoing basis from agency leadership in a timely manner regarding their implementation progress or roadblocks they are facing as they work to enact the actions identified via the landmark National Strategy.

Strengthen Federal Level Coordination to Update and Improve the National Strategy

Our Ask: Support dedicated allocation of resources necessary to strengthen cross-agency federal coordination around National Strategy implementing and updating efforts, monitor and evaluate the impact of these efforts, and to support funding mechanisms that help states, agencies, and non-profit organizations implement the National Strategy.

Benchmark for Success: HHS has sufficient and dedicated resources to support the cross-departmental coordination needed to regularly update and republish the National Strategy based on a thorough and accurate assessment of changes in the landscape and to put the strategy into action by providing resources to agencies, organizations, and states.

Rationale: The nearly 350 federal actions identified in the National Strategy demonstrate the span of agencies across the federal government with a role in implementation. Without appropriate resources to track and measure implementation efforts, and understand the outcomes and impact of those measures, HHS will be limited in its ability to accurately reflect changes in the landscape while attempting to ensure the strategy is up to date on a biennial basis. Increased resources are needed to ensure a process is developed and put in place that allows agency leadership to identify and report on anticipated and actualized outcomes of federal agency actions that align with implementation efforts. By providing outcomes measures, the National Strategy will have established efficacy that can be further refined, and an updated National Strategy can be developed with a clear picture of what is being accomplished because of the actions federal agencies are taking.

To ensure the National Strategy evolves effectively over time, the President's annual budget must include increased appropriations requests in the HHS budget to allow adequate and ongoing support of the RAISE National Strategy process, to track implementation efforts, and to put the strategy into action by providing resources to agencies, states, and non-profit organizations serving family caregivers. As the RAISE Family Caregiving Advisory Council further addresses the issues faced by families by updating the National Strategy, continued and increased appropriations are critical in the effort to track and refine actions that can be taken to recognize and support family caregivers moving forward. We request continued prioritization and an increase in the appropriations requests for the HHS budget that will be needed to sustain the efforts of the RAISE Family Caregiving Advisory Council in updating the National Family Caregiving Strategy. Additionally, we recommend that HHS develop a publicly accessible, online dashboard to educate agencies, policymakers, public policy stakeholders, and family caregivers about the implementation status of actions across agencies. This dashboard can help promote transparency and coordination as the National Strategy is refined.

<u>Highlight the Impacts of Caregiving on Families, Communities, and the Economy Across Sectors</u>

Our Ask: Continue to leverage the Administration's bully pulpit and platform to put the spotlight on unpaid family caregivers and bipartisan or cross-sector solutions to support them.

Benchmark for Success: Actions within the National Strategy across sectors are highlighted and leaders with the power and influence to drive implementation have publicly prioritized and committed to supporting this population in their own way.

Rationale: Although federal agencies have committed to taking action to implement the National Strategy soon, the National Strategy clearly outlines actions that require additional Congressional authority, regulatory improvements, and actions by states and the private sector. The whole-of-society approach to the National Strategy acknowledges that the federal government is not the only entity with a role in implementation efforts. Furthermore, prioritization around actions with the potential for highest impact will vary based on the various sectors with a role in building the nationwide infrastructure that is needed. It will be critical for leadership on the national level to come together to define these priorities and establish a plan of action that is realistic and responsive to the needs of this population, particularly regarding influential figures in the fields of healthcare and financial security.

We urge the White House and the Biden-Harris Administration to play a leading role in putting a spotlight on unpaid family caregivers and their importance to advancing our nation's health and economic security by integrating family caregiving issues into future administrative action, external communications, and events. We urge the administration to consider hosting a White House Forum on Family Caregivers to highlight the progress made with the National Strategy and to catalyze private sector, philanthropic, and bipartisan congressional action in support of America's 53 million unpaid family caregivers. Such an event could be tied to National Family Caregivers Month in November.

Thank you for your commitment to addressing these issues and for your dedicated work to make caregiving more sustainable, dignified and equitable for all Americans.

As a community dedicated to lifting the voices of family caregivers, we stand ready to support the Administration's immediate and longer-term efforts to strengthen the bond of caregiving that connects American families and communities. If you or our staff have any questions, please contact Michael Wittke, Vice President, Policy & Advocacy, at mike@caregiving.org.

Respectfully,

AARP* Caregivers on the Homefront

Advocord Caregiving.com

Agnes McCarthy Caregiver Foundation

CareWise Solutions

Alzheimer's Association/Alzheimer's Impact
Movement*

Caring Across Generations*

American Cancer Society/ACS Cancer

Diverse Elders Coalition*

Action Network* Elizabeth Dole Foundation*

American Geriatrics Society Empowered Caregiver Community

American Heart Association Genentech

The Arc* Gimme A Break

Autism Society of America Greater Wisconsin Agency on Aging Resources, Inc.

Canary Health The John A. Hartford Foundation

Careforth Justice in Aging

LEAD Coalition (Leaders Engaged on Alzheimer's Disease)

Lincoln Health Services LLC

Lindsay Institute for Innovation in Caregiving

National Alliance for Caregiving*

National Asian Pacific Center on Aging

National Council on Aging*

National Health Council*

National Respite Coalition

New Mexico Caregivers Coalition

North Carolina Coalition on Aging

North Carolina Serious Illness Coalition

Riccio Pick Me Ups

Rosalynn Carter Institute for Caregivers*

Self-Management Resource Center

The Gerontological Society of America

Triage Cancer

TrustedRiders Inc.

USAging*

Wisconsin Aging Advocacy Network

Wisconsin Family and Caregiver Support Alliance (WFCSA)

*Notes Act on RAISE Steering Committee member