

VIA ELECTRONIC DELIVERY

The Honorable Chuck Schumer Majority Leader United States Senate

The Honorable Kevin McCarthy Speaker U.S. House of Representatives The Honorable Mitch McConnell Minority Leader United States Senate

The Honorable Hakeem Jeffries Minority Leader U.S. House of Representatives

June 13, 2023

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

Dear Leader Schumer, Leader McConnell, Speaker McCarthy, and Leader Jeffries:

On behalf of the National Alliance for Caregiving (NAC), and the below members of the Act On RAISE campaign, we are writing to request your assistance in improving the state of caregiving in the U.S. Specifically, we ask you to support the goal of our newly launched campaign which is to ensure that the implementation of the National Strategy to Support Family Caregivers (National Strategy) 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 health care in the U.S. in 2021.

The National Strategy was developed jointly by the advisory councils created by the bipartisan RAISE Family Caregivers Act and the Supporting Grandparents Raising Grandchildren Act, with extensive input from the public, including family caregivers and the people they support. The National Strategy is the product of comprehensive analysis and input from a federally appointed Advisory Council, 15 federal agencies, and more than 150 organizations representing a range of stakeholders from across the nation. The National Strategy demonstrates that caregiving truly connects us all.

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

We ask for your 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 Impacts of Caregiving on Families, Communities, and the Economy

Accelerate Implementation of the 350 Federal Actions within the National Strategy

Our Ask:

Help provide oversight to accelerate implementation of National Strategy's federal actions with the potential for highest impact, address gaps, and ensure federal agencies are measuring and reporting on their activities on a regular basis.

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.

We urge you to work with appropriate federal agencies to ensure that these actions are implemented on a timely basis. We request that you ask HHS to invite those federal agencies which have made commitments regarding National Strategy implementation to participate in upcoming RAISE Family Caregiving Advisory Council public meetings so they can report on their progress and engage directly in dialogue with RAISE Family Caregiving 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 Congressional 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 implementation 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 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 outcome 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 annual budget must include increased appropriations for HHS to support 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 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 appropriations 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.

Highlight the Impacts of Caregiving on Families, Communities, and the Economy

Our Ask: Advance opportunities for bipartisan policy changes and investments that are needed to implement the National Strategy by going beyond existing congressional authorities and promote the need to address issues facing family caregivers across the lifespan on an ongoing basis.

Benchmark for Success: Policymakers are equipped to act on bipartisan opportunities going beyond existing congressional authorities or providing necessary resources to implement National Strategy actions. Incentives and dedicated resources are in place to implement the actions in the National Strategy on the federal and state level, as well as in the private sector.

Rationale: Although federal agencies have committed to taking action to implement the National Strategy a significant limitation to the RAISE Family Caregivers Act and the National Strategy is that additional Congressional action is required to extend authorities and either increase or secure newly appropriated funds to implement key components of the strategy. Family caregiving is an issue that spans partisan lines. As the Strategy is implemented—and as the nation more fully comes to understand and respond to the challenges faced by family caregivers— lawmakers will be called upon to propose legislative changes to better support family caregivers. We view the Strategy as a call-to-action for lawmakers at all levels of government, however, the Strategy specifically proposes a list of recommendations for federal policy makers and legislators to enhance support for family caregivers. These recommendations touch on all five goals of the Strategy and highlight the need for action on a wide range of policy proposals from tax incentives, investments in the direct care workforce, strengthening existing community-based programs, and implementing new programs such as paid family and medical leave. Policy changes on the federal level that garner bipartisan support will be needed for the National Strategy to result in a significant positive impact on this population.

To further advance policy and programmatic priorities, we request a bipartisan, bicameral resolution expressing the will of Congress to advance priorities that can be tracked to actions outlined in the National Strategy. This will allow the Congress to build on what agencies are implementing under existing authority and potentially provide insight into pathways that can lead to additional action. Such activities 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 your immediate and longer-term efforts to strengthen the bond of caregiving that connects American families and communities. If you or your staff have any questions, please contact Michael Wittke, Vice President, Policy & Advocacy, at mike@caregiving.org.

Respectfully,

AARP*

American Geriatrics Society

Advocord

American Heart Association

Agnes McCarthy Caregiver Foundation

The Arc*

Alzheimer's Association/Alzheimer's Impact

Movement*

Autism Society of America

American Cancer Society/ACS Cancer

Canary Health

Action Network*

Careforth

North Carolina Coalition on Aging

Caregivers on the Homefront North Carolina Serious Illness Coalition Riccio Pick Me Ups Caregiving.com CareWise Solutions Rosalynn Carter Institute for Caregivers* Caring Across Generations* Self-Management Resource Center Diverse Elders Coalition* The Gerontological Society of America Elizabeth Dole Foundation* **Triage Cancer** TrustedRiders Inc. **Empowered Caregiver Community** Genentech USAging* Gimme A Break Wisconsin Aging Advocacy Network Greater Wisconsin Agency on Aging Wisconsin Family and Caregiver Support Resources. Inc. Alliance (WFCSA) The John A. Hartford Foundation *Notes Act on RAISE Steering Committee member 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**