November 6, 2019

The Honorable Lance Robertson, M.P.A. 
RAISE Council Chair
Administrator and Assistant Secretary for Aging
Administration for Community Living
U.S. Department of Health and Human Services

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Distinguished Members of the
RAISE Family Caregiving Advisory Council
Administration for Community Living
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Dear Colleagues:

We applaud the formal establishment of the newly-developed RAISE Family Caregiving Advisory Council, a major milestone for the recently enacted Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act of 2017. We also applaud the efforts of the dedicated advocates and policy makers involved in passing this encouraging legislation, including the official bill sponsors U.S. Senator Susan Collins (R-ME) and U.S. Representative Gregg Harper (R-MS).

As a community dedicated to providing a voice for family caregivers, we stand at the ready to support the work of the Administration for Community Living (ACL) and the RAISE Family Caregiving Advisory Council in the effort toward implementation of policies that will support America’s caregivers.

There are two critical components of success from our vantage point working with families:

1. The national family caregiving strategy must be inclusive of all caregivers of adults and children across the lifespan. This must include caregivers who have a significant relationship with, and who provide a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation.

2. Caregiving isn’t going away – and neither should the RAISE Family Caregiving Advisory Council. We urge immediate action to preserve this Council and ensure it meets its intended purpose by extending or altogether eliminating the Council’s expiration date.

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. 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 and respite 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 Council should explicitly address those caring for individuals with serious illnesses,
rare diseases, combat-related injuries or illnesses, and those managing physical or cognitive impairment at any age. Likewise, ongoing alignment with existing Advisory Committees working on related issues, notably the National Alzheimer’s Project Act Advisory Council on Alzheimer’s Research, Care, and Services and the U.S. Department of Veterans Affairs’ Veterans' Family, Caregiver, and Survivor Advisory Committee.

Second, time is not a luxury for the Advisory Council. The RAISE Family Caregivers Act became law on January 22, 2018. The initial public meeting and swearing in of the Council members was held on August 28, 2019. A sunset provision was included in Section 6 of the bill which states the authority and obligations established by the bill shall terminate 3 years after the date of enactment of the legislation. It is imperative to ensure that the Advisory Council will have an appropriate amount of time to address the various and complex needs of caregivers across the lifespan and across the conditions their care recipients encounter. The need to address the challenges facing America’s family caregivers as our population ages, fewer caregivers are available and our health care system transitions to a more person and family-centered model will only increase with time. We urge ACL to work with us to seek a legislative solution or possible Administrative change to preserve this Council and ensure it meets its intended purpose by extending or altogether eliminating the Council’s expiration date.

We are excited to build on the momentum driven by the RAISE Family Caregivers Act and continue to explore ways that family caregivers could be supported with bipartisan solutions. Now is the time to take proactive steps to ensure the development of a support infrastructure and productive social and health care systems equipped to serve working caregivers, caregivers of wounded veterans, spousal caregivers, pediatric caregivers, older adult and youth caregivers, long-distance caregivers, higher-hour caregivers and all others in need. The RAISE Family Caregivers Act and the Advisory Council are first steps, we must seize this moment and work together to embark on the laborious but rewarding effort to implement real policy solutions.

If you have any questions, please feel free to contact John Schall, President of Caregiver Voices United and CEO of Caregiver Action Network, at JSchall@CaregiverAction.org or C. Grace Whiting, President and CEO of National Alliance for Caregiving, at grace@caregiving.org.

American Association of Caregiving Youth
Caregiver Action Network
Caregiver Voices United
The Elizabeth Dole Foundation
Family Caregiver Alliance
Men Against Breast Cancer
National Alliance for Caregiving
Rosalynn Carter Institute
Well Spouse Association
National Respite Coalition

Voices United is a 501(c)4 organization (EIN 47-2882132) that advocates for family caregivers who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age.