



The Honorable Susan Collins
Chairman
U.S. Senate Special Committee on Aging
G-31 Dirksen Senate Office Building
Washington, DC 20510

November 15, 2019

Dear Chairman Collins:

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued leadership on issues and legislation important to Americans living with Alzheimer's and other dementias, and their caregivers. In addition, thank you for working in a bipartisan manner to reauthorize this important program, including the hearing held by the Senate Special Committee on Aging. We are proud to support this draft of the Older Americans Act (OAA) reauthorization and are pleased to highlight several provisions that are critical to persons living with dementia, families, and their caregivers.

We strongly support the inclusion in the draft of language codifying existing authority to provide services to individuals living with younger-onset Alzheimer's disease under the National Family Caregiver Support Program and the Long-Term Care Ombudsman Program. We are very appreciative for the inclusion of these key elements of the Younger-Onset Alzheimer's Disease Act (S. 901/H.R. 1903).

There are approximately 5.8 million Americans living with Alzheimer's disease. The vast majority of those individuals are over the age of 65, however, approximately 200,000 Americans are under the age of 65 living with younger-onset Alzheimer's disease. Individuals living with younger-onset face unique challenges when it comes to family, work, and finances. They may be parenting young children at home, or still be working as the primary income provider for their families. Due to their young age, they may have more trouble receiving an accurate diagnosis, and even family and friends might question their diagnosis. The stigma associated with younger-onset Alzheimer's can have a significant impact on their well-being and quality of life.

Since 97 percent of all people living with Alzheimer's are age 65 or older, current Alzheimer's support infrastructure focuses exclusively on seniors. As a result, few supportive services are available to those with younger-onset. With other diseases — like heart disease, diabetes, and even cancer — many people living with them are middle-aged and there is a large support structure available to them. Those same support structures are not available for the individuals living with younger-onset Alzheimer's disease. The services provided under the OAA are particularly helpful for individuals with younger-onset Alzheimer's disease and related dementias who need assistance with activities of daily living.

The Younger-Onset Alzheimer's Disease Act is consistent with the *National Plan to Address Alzheimer's Disease*. The Advisory Council on Alzheimer's Research, Care, and Services, which is responsible for updating and implementing the Plan, has noted that persons living with younger-onset Alzheimer's face unique challenges in accessing care. In the 2017 National Plan,

the Advisory Council recommended that Congress amend the OAA to allow additional services to be provided to younger adults living with dementia.

The Alzheimer's Association and AIM also deeply appreciate the bill's extension of the authorization for the RAISE Family Caregivers Act from 3 years to 8 years. We have been strong advocates for the RAISE Family Caregivers Act since it was introduced in Congress. There has been a delay in the implementation of the Act and the decision to extend the authorization allows the Department of Health and Human Services to better develop a national strategy for education and training, long-term services and supports, and financial stability and security for caregivers.

For millions of Americans caring for individuals with Alzheimer's and other dementias the emotional, physical, and financial costs can be overwhelming. Caregivers of people with dementia report higher levels of stress, depression, and worse health outcomes than those providing care to individuals without dementia. As a result, Alzheimer's caregivers incurred \$11.8 billion in additional health costs last year. We appreciate the bill prioritizing this important program.

We also applaud the bill's strengthening of caregiver assessments. In 2018, more than 16 million unpaid caregivers provided 18.5 billion hours of care valued at nearly \$234 billion and face the challenges noted above. Eighty-three percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers. Nearly half of all caregivers who provide help to older adults do so for someone living with Alzheimer's or another dementia. Alzheimer's takes a devastating toll on caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care.

These dedicated caregivers would greatly benefit from increased resources, training, and support to help them navigate the strain of caregiving and improve their health and quality of life. The proposed changes would provide these caregivers with much-needed resources through the National Family Caregiver Support Program, increase the use of caregiver assessments, and identify best practices relating to the programs. These important actions will enhance support for caregivers through skills building, increased resources and information, respite care, counseling, and other helpful benefits.

Finally, the Association and AIM appreciate your commitment to supporting individuals facing social isolation with the inclusion of a report on social isolation. Social isolation is an issue within the aging community as a whole, and particularly in the Alzheimer's and related dementias community. Studies have found that support groups can decrease social isolation and increase social support, ability to accept the diagnosis, cope with symptoms, improve quality of life, and enhance family communication (Alzheimer's Association *Dementia Care Practice Recommendations*, 2018). Support programs offered through the National Family Caregiver

Support Program can work to decrease social isolation. We appreciate the bill's inclusion of a study on the effectiveness of these programs.

Again, thank you for your leadership in ensuring OAA's reauthorization, which will improve the quality of care for people living with Alzheimer's. If you have any questions, please contact Rachel Conant, Vice President of Federal Affairs, at rconant@alz-aim.org or at 202.638.7121.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Egge', with a long horizontal flourish extending to the right.

Robert Egge
Chief Public Policy Officer
Executive Vice President, Government Affairs
Alzheimer's Association