



The Honorable Bernie Sanders
Chairman
United States Senate Committee on
Health, Education, Labor and Pensions
428 Dirksen Senate Office Building
Washington, D.C. 20510

The Honorable Bill Cassidy, M.D.
Ranking Member
United States Senate Committee on
Health, Education, Labor and Pensions
428 Dirksen Senate Office Building
Washington, D.C. 20510

March 21, 2024

RE: Information from Stakeholders on the Reauthorization of the Older Americans Act (OAA) – Alzheimer’s Association and Alzheimer’s Impact Movement

Dear Chairman Sanders and Ranking Member Cassidy:

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 with Alzheimer’s and other dementias, and their caregivers. We appreciate the opportunity to provide input on the reauthorization of the Older Americans Act (OAA), which will ensure our aging population, including individuals living with Alzheimer’s disease and other dementias, may continue receiving support services vital to remaining independent and aging in place.

Background

Founded in 1980, the Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer’s care, support, and research. Our mission is to eliminate Alzheimer’s and other dementia through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. The Alzheimer’s Impact Movement is the Association’s advocacy affiliate, working in a strategic partnership to make Alzheimer’s a national priority. Together, the Alzheimer’s Association and AIM advocate for policies to fight Alzheimer’s disease, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

An estimated 6.9 million Americans age 65 and older are living with Alzheimer’s dementia in 2024. The total cost of caring for people with Alzheimer’s and other dementias in the United States is projected to reach \$360 billion in 2024. In addition, family and friends provided nearly \$350 billion (\$346.5) in unpaid caregiving in 2023. Medicare and Medicaid are expected to cover \$231 billion, or 64%, of the total health care and long-term care payments for people with

Alzheimer's or other dementias. Out-of-pocket spending is expected to be \$91 billion, or 25 percent of total payments. Total payments for health care, long-term care, and hospice care for people living with dementia are projected to increase to nearly \$1 trillion in 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

When considering policies to support our aging population, it is critical that the Committee takes into account the unique needs of individuals living with Alzheimer's and other dementia. In response, we encourage the Committee to consider expanding funding for dementia-specific programs, enhancing caregiver support services, and promoting community-based initiatives that address social isolation. These priorities are crucial for improving the quality of life for individuals with Alzheimer's and other dementias.

Supporting Dementia Caregivers

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. And, for the over 11 million Americans caring for individuals with Alzheimer's and other dementias, the emotional, physical, and financial costs can be overwhelming. In 2023, the 11.5 million unpaid caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours of unpaid help. 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.

Community services provided under the OAA offer invaluable support for individuals living with dementia, and, due to the unique challenges they face, it is paramount to continue prioritizing care coordination efforts within communities during the reauthorization process. Dementia often requires a multi-disciplinary approach involving medical professionals, caregivers, social workers, and community support services. Effective coordination helps caregivers navigate the complex healthcare and social service systems and ensures that caregivers and health care professionals collaborate seamlessly, providing comprehensive care tailored to their individual needs. Challenges such as cognitive decline, communication difficulties, and fluctuating symptoms necessitate specialized strategies for coordination. Initiatives promoting dementia-friendly communities and caregiver education programs play crucial roles in enhancing coordination and support networks. By prioritizing and refining care coordination, communities can offer a better quality of life and support for individuals living with dementia and their caregivers.

When developing legislation to reauthorize OAA, we ask that the Committee consider provisions to emphasize the unique and growing support services needed by Alzheimer's and dementia caregivers. We are grateful for the Committee's longstanding work to enhance access to the National Family Caregiver Support Program, and the swift implementation of the country's first

National Family Caregiver Strategy as created by the Family Caregiving Advisory Council established by the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act.

These dedicated caregivers greatly benefit from increased resources, training, and support to help them navigate the strain of caregiving and improve their health and quality of life. Congress can further build upon these efforts by increasing funding for caregiver support programs, expanding access to respite care services, and integrating dementia-specific training for caregivers.

Strengthening the Dementia Care Workforce

The changing needs of the older adult population, including those with dementia, require a more holistic approach from the aging network - this involves increasing access to dementia-friendly services, promoting age-friendly communities, and integrating healthcare and social services to support aging in place. We ask that the Committee consider policies to reduce barriers and ensure individuals living with dementia have adequate access to long-term care and home- and community-based services (HCBS). People living with Alzheimer's and other dementias make up a significant portion of all long-term care residents, comprising 46 percent of all residents in nursing homes and 36 percent of all individuals using home health services. Given our constituents' intensive use of these services, the quality of this care is of the utmost importance. As a result, we encourage the Committee to consider policies to enhance long-term care and support services for the growing number of Americans with Alzheimer's and other dementias who are eligible to receive OAA services.

A strong dementia care workforce is needed to ensure quality care for aging populations. For example, individuals living with dementia make up a large proportion of all elderly people who receive home- and community-based services, and 31 percent of individuals using adult day services have dementia. Access to these services can help people with dementia live in their homes longer and improve the quality of life for both themselves and their caregivers. In-home care services, such as personal care services, companion services, or skilled care, can allow individuals living with dementia to stay in familiar environments and be of considerable assistance to caregivers. Adult day services can provide social engagement and assistance with daily activities. When drafting language to reauthorize the OAA, we urge the Committee to consider the unique needs of individuals with Alzheimer's and other dementias directly benefit from a well-trained workforce specialized in dementia care.

Conclusion

The Alzheimer's Association and AIM appreciate the Committee's steadfast support and commitment to advancing issues important to the millions of individuals living with Alzheimer's and other dementias, as well as their caregivers. We look forward to working with you as the

Older Americans Act reauthorization effort moves through the legislative process and again ask that you keep individuals living with dementia in mind as you develop this bill.