

### Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record

# United States Senate Committee on Health, Education, Labor and Pensions Hearing on "The Older Americans Act: Supporting Efforts to Meet the Needs of Seniors"

#### March 7, 2024

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Committee on Health, Education, Labor and Pensions (HELP) hearing entitled "The Older Americans Act: Supporting Efforts to Meet the Needs of Seniors." The Association and AIM thank the Committee for its continued leadership on issues important to the millions of individuals living with Alzheimer's and other dementias and their caregivers. This statement highlights the importance of policies and programs within the Older Americans Act (OAA) that can help meet the unique needs of our nation's growing number of Americans living with Alzheimer's and other dementias.

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 dementias 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. AIM 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 6.7 million Americans age 65 and older lived with Alzheimer's dementia in 2023. Total payments for all individuals with Alzheimer's or other dementias are estimated at \$345 billion (not including unpaid caregiving) in 2023. Medicare and Medicaid were expected to cover \$222 billion or 64 percent of the total health care and long-term care payments for people with Alzheimer's or other dementias, which are projected to increase to more than \$1.1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

As the prevalence of Alzheimer's disease and other dementias increases, so does the need for care and support services for those living with these diseases. The OAA provides federal funding and the necessary infrastructure to deliver vital support programs and social services to our nation's seniors, including those with Alzheimer's disease. These critical programs are utilized by millions of low-income Americans and provide for such services as home-delivered and congregate nutrition services; in-home supportive services; transportation; caregiver support; community service employment; health and wellness programs; the long-term care ombudsman program; services to prevent the abuse, neglect, and exploitation of older adults;

and other supportive services. Twenty-four percent of older individuals with Alzheimer's disease and other dementias who have Medicare are also eligible for Medicaid, punctuating the need within the Alzheimer's community for such programs as Meals on Wheels and the National Family Caregiver Support Program.

We are grateful that the Supporting Older Americans Act of 2020 (P.L. 116-131) included the Younger Onset Alzheimer's Disease Act, championed by Senator Susan Collins (R-ME), to codify 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. 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 and accessing care.

#### **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 2022, caregivers of people living with Alzheimer's or other dementias provided an estimated 18 billion hours of unpaid care, a contribution valued at \$339.5 billion. 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.

## Strengthening the Dementia Care Workforce

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 49 percent of all residents in nursing homes and 34 percent of all residents in assisted living communities and other residential care facilities. 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.