



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

### **United States Senate Special Committee on Aging Hearing on "Empowering People with Disabilities to Live, Work, Learn, and Thrive"**

**December 12, 2024**

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging hearing on "**Empowering People with Disabilities to Live, Work, Learn, and Thrive.**" We thank the Committee for its continued leadership on issues crucial to individuals living with Alzheimer's and other dementias. This statement underscores the critical role of services needed to empower individuals living with Alzheimer's and other dementias to achieve independence and thrive.

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. 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.

Nearly seven million Americans age 65 and older are living with Alzheimer's dementia in 2024. Total payments for all individuals with Alzheimer's or other dementias are estimated at \$360 billion (not including unpaid caregiving) in 2024. Medicare and Medicaid are expected to cover \$231 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 nearly \$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.

#### **Home- and Community-Based Services: Needs of the Alzheimer's and Dementia Community**

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as possible. In fact, an estimated 65 percent of people with Alzheimer's live in the community, and states are driving much of the development of and better access to Home- and Community-Based Services (HCBS). These services can reduce long-term costs and provide person-centered care, including respite and adult day care, in home and community settings, regardless of age or other state-supported programs. These programs are indispensable in providing services to support people with dementia and their caregivers, enabling them to remain in their homes and communities longer while improving their quality of life.

People living with Alzheimer's or other dementias make up a large proportion of all elderly people who receive adult day services and nursing home care. Additionally, 32 percent of individuals using home health services have Alzheimer's or other dementias. Persons affected by dementia use a wide range of long-term supports and services, for example:

*Adult day services.* Twenty-eight percent of individuals using adult day services have Alzheimer's or other dementias, and ten percent of adult day services specialize in caring for individuals with these conditions. The median cost of adult day services is \$75 per day, and it has increased by 1.5 percent annually over the past five years.

*Respite.* Given the demands and responsibilities placed on caregivers, respite is critical to their health and well-being, and may allow individuals with dementia to remain in the home longer. The use of respite care by dementia caregivers has increased substantially, from 13 percent in 1999 to 27 percent in 2015. This is consistent with the growing demand the Alzheimer's Association hears from our constituents. Yet the availability of respite programs in the community is limited.

### **Home- and Community-Based Services: The Impact on Family Caregivers**

Family caregivers, who are often the primary support for individuals with Alzheimer's or other dementias, play an essential role in maintaining the quality of life for their loved ones. Nearly 83 percent of older adults in the United States rely on unpaid care from family, friends, and other caregivers. Of these, nearly half are caring for someone with Alzheimer's disease or another dementia. 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. Alzheimer's takes a devastating toll on caregivers.

Caregivers for those living with Alzheimer's — usually family and friends — face substantial challenges. In 2023, more than 11 million unpaid caregivers provided an estimated 18.4 billion hours of unpaid care to people with Alzheimer's and other dementias, valued at over \$346.6 billion. Of the unpaid Alzheimer's and dementia caregivers, 86 percent have provided care for at least the past year, and well over half have been providing care for four or more years. Approximately one-fourth of Alzheimer's and dementia caregivers are “sandwich generation” caregivers — caring for both someone with the disease and a child or grandchild.

Home- and community-based services allow people with dementia to remain in their homes while providing family caregivers with much-needed support. These services empower caregivers to provide quality care for their loved ones while allowing them to manage and improve their own health.

One way the Association is helping caregivers of individuals with Alzheimer's is by providing a 24/7 Helpline (800.272.3900) available around the clock, 365 days a year. Through this free service, specialists and master's-level clinicians offer confidential support and information to

people living with dementia, caregivers, families, and the public. The Fiscal Year 2024 Consolidated Appropriations Act (P.L. 118-42) allocated \$2 million for the Alzheimer's Call Center, and we look forward to working with Congress to continue funding this vital resource to individuals living with the disease and their caregivers.

### **Direct Care Workforce in Long-Term Care Settings**

As the prevalence of Alzheimer's disease increases, so does the need for members of the paid dementia care workforce. Shortages in direct care workers will place an even bigger burden on family and friends who provide unpaid care — already an effort equivalent to nearly \$257 billion annually. The United States will have to nearly triple the number of geriatricians to effectively care for the number of people projected to have Alzheimer's in 2050, while efforts to increase recruitment and retention remain slow. In 48 U.S. states, double-digit percentage increases in home health and personal care aides will be needed by 2028 to meet demand. From 2016 to 2026, the demand for direct care workers is projected to grow by more than 40 percent, while their availability is expected to decline.

The [\*Alzheimer's Association's Dementia Care Practice Recommendations\*](#) include the following recommendations specific to the workforce: (1) staffing levels should be adequate to allow for proper care at all times — day and night; (2) staff should be sufficiently trained in all aspects of care, including dementia care; (3) staff should be adequately compensated for their valuable work; (4) staff should work in a supportive atmosphere that appreciates their contributions to overall quality care because improved working environments will result in reduced turnover in all care settings; (5) staff should have the opportunity for career growth; and (6) staff should work with families in both residential care settings and home health agencies. Additionally, consistent assignment is an important component of quality care for staff working with residents with dementia.

While much of the training for long-term care staff is regulated at the state level, we encourage the Committee to consider proposals that support states in implementing and improving dementia training for direct care workers, and their oversight of these activities. Training policies should be competency-based, should target providers in a broad range of settings and not be limited to dementia-specific programs or settings, and should enable staff to (1) provide person-centered dementia care based on a thorough knowledge of the care recipient and their needs; (2) advance optimal functioning and high quality of life; and (3) incorporate problem-solving approaches into care practices.

We also urge the Committee to support states in the following efforts: (1) any training curriculum should be delivered by knowledgeable staff that has hands-on experience and demonstrated competency in providing dementia care; (2) continuing education should be offered and encouraged; and (3) training should be portable, meaning that these workers should have the opportunity to transfer their skills or education from one setting to another.

The Alzheimer's Association and AIM look forward to working with the Committee to shape specific proposals to better train and support the direct care workforce to provide the highest-quality support for individuals living with dementia. In the meantime, we encourage you to keep residents living with dementia top-of-mind as you continue this important work.

**Conclusion**

The Alzheimer's Association and AIM deeply appreciate the Committee's continued commitment to advancing issues vital to the millions of families affected by Alzheimer's and other dementias. We look forward to working with the Committee in a bipartisan way to address the critical challenges facing the dementia community.