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

United States Senate Special Committee on Aging Hearing on "Aging in Place: The Impact of Community during the Holidays"

December 3, 2025

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 "Aging in Place: The Impact of Community during the Holidays." The Association and AIM thank the Committee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers. We especially recognize the significant role that social isolation, senior loneliness, and limited community connection play in shaping outcomes for people living with dementia — challenges that become more acute during the holiday season. Among other issues, this statement highlights the value of long-term care settings as well as home- and community-based services (HCBS), helping individuals living with Alzheimer's and other dementia remain in their homes as long as possible.

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.

The burden of Alzheimer's on individuals and families continues to grow. Over 7 million Americans aged 65 and older lived with Alzheimer's dementia in 2024. Total payments for all individuals with Alzheimer's or other dementias are estimated at $384 billion (not including unpaid caregiving) in 2024. Medicare and Medicaid are expected to cover $246 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 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only becoming more urgent.

Some researchers have surmised that factors such as social isolation from COVID-19 lockdowns, for example, no-visitor policies in long-term care facilities, and increased intensive hospitalizations may increase dementia risk at the population level, but research in the coming years will be necessary to confirm this and examine whether the impact is time-limited or long-term. Community connection is a critical part of both care and prevention.

We encourage the Committee to keep the following recommendations in mind to strengthen the support of the growing number of families affected by Alzheimer's, especially given the unique challenges the dementia care community faces in HCBS and long-term care settings. In

particular, efforts to reduce social isolation and address senior loneliness must be centered as essential components of high-quality dementia care and successful aging in place.

Use and Costs of Long-Term Care Services

Long-term care services include home- and community-based services and services delivered in assisted living residences and nursing homes, and the costs have grown consistently across settings. In 2023, nonmedical home care cost a median of $33 per hour and $6,292 per month, while homemaker services averaged $30 per hour and $5,720 per month. The median cost of adult day services was $95 per day. Assisted living averaged $5,350 per month, or $64,200 per year. Nursing homes were the most expensive: a private room averaged $320 per day ($116,800 per year) and a semi-private room averaged $285 per day ($104,025 per year). Few individuals with Alzheimer's or other dementias have sufficient long-term care insurance or can afford to pay out of pocket for long-term care services for as long as the services are needed.

The fourth most common chronic condition in participants using adult day services is Alzheimer's disease or other dementias, and 25 percent of all individuals using adult day services have Alzheimer's or other dementias. Fourteen percent of adult day service centers in the U.S. specialized in caring for individuals with Alzheimer's disease or other dementias in 2020, up from 10 percent in 2016. These services are also essential in combating senior loneliness by creating reliable touchpoints for social interaction and community engagement. By prioritizing policies supporting caregivers and combating social isolation and senior loneliness, we can help the aging population live longer, healthier lives.

Numerous states have recognized the importance of prioritizing dementia care coordination as part of a comprehensive system of diagnosis, treatment and care. Following a model set by Wisconsin, states such as Georgia, Indiana, Maryland, South Carolina, and Louisiana have established Dementia Care Specialists Programs. The Alzheimer's Association was proud to support each state in advancing these efforts and has ensured newly employed dementia care specialists have the training needed to effectively support people living with dementia and their families. All of these states have appropriated state funds to bolster their existing Aging or Public Health infrastructure with dedicated staff to provide community education, support families through the diagnosis process and connect individuals and caregivers to resources. States like Tennessee, Kentucky and Nevada have utilized limited federal grant funding in similar ways. In Florida, for example, the Florida Alzheimer's Center of Excellence (FACE) helps people with Alzheimer's and other dementias age in place and helps support families by bolstering support for caregivers. With trained specialists, families can access support to access a diagnosis and care, and get connected to clinical trials.

The Impact on Family Caregivers

While 83 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 help older adults do so for someone with Alzheimer's 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. Unpaid caregivers provided care valued at more than $22 billion in each of the four most populous states — California, Texas, Florida and New York.

Caregivers for those living with Alzheimer's face substantial challenges. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties. These challenges are often magnified during the holiday season, when disruptions in routine and reduced support can increase caregiver stress and exacerbate social isolation. 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.

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as possible, and HCBS 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 giving them an opportunity to manage and improve their own health. They also help reduce caregiver isolation — an often-overlooked challenge that affects emotional well-being and the sustainability of care.

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. Yet the availability of respite programs in the community is limited. We are proud to support the bipartisan Lifespan Respite Care Reauthorization Act of 2025 (S. 830/H.R. 2560), led by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI), and Representatives Nick Langworthy (R-NY-23) and Jill Tokuda (D-HI-02), to meet this growing demand.

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 Full-Year Continuing Appropriations and Extensions Act (P.L. 119-4) allocated $2 million for the Alzheimer's Call Center, and we look forward to working with the Committee to continue funding this vital resource to individuals living with the disease as well as their caretakers.

Strengthening the Direct Care Workforce

As we enter a new era of Alzheimer's treatment, access to timely and accurate detection and diagnosis is more critical than ever. And as the prevalence of Alzheimer's disease increases, so does the need for members of the paid dementia care workforce. Nearly 900,000 additional direct care workers will be needed between 2022 and 2032 — more new workers than in any other single occupation in the United States. For example, in New York, nearly 13 percent of all individuals aged 65 and older have Alzheimer's disease, and a nearly 29 percent increase in the workforce is needed to meet the expected demand in 2032. And in Florida, meeting the expected demand in 2050 would require an increase of over 168 percent. Meeting this demand requires a collaborative, multidisciplinary workforce that includes primary care providers, neurologists, geriatric specialists, registered nurses, social workers, and direct care professionals such as personal care aides, home health aides, and nursing assistants. Each plays a critical role in identifying cognitive concerns, diagnosing and treating the underlying cause, monitoring disease progression, and delivering hands-on care and support across the disease continuum.

Beyond these distinct tasks, direct care workers play a broader role in promoting nutrition, exercise, functional ability, social engagement and emotional well-being for those living with dementia. With training in active listening, empathic response and other relevant skills, direct care workers can reduce social isolation and provide emotional support and, with additional training, help prevent or reduce distress associated with dementia through the delivery of person-centered, non-pharmacological interventions. Their daily presence is often one of the most consistent sources of social connection for individuals with dementia aging in place.

Technology-enabled collaborative learning and capacity-building models, like Project ECHO, use a hub-and-spoke approach by linking expert specialist teams at a 'hub' with the 'spokes' of health providers in local communities to increase on-the-ground expertise. Using case-based learning, Project ECHO models can improve the capacity of providers, especially those in rural and underserved areas, on how to best meet the needs of people living with many chronic conditions, including Alzheimer's and other dementia. The Alzheimer's and Dementia Care ECHO program, led by the Alzheimer's Association, has trained more than 2,000 health care professionals since 2018. Ninety-five percent of those professionals made changes to the way they care for patients as a result of what they learned from ECHO. Quality care delivered by trained providers leads to better health outcomes for individuals and caregivers and puts less strain on health systems. Project ECHO programs have shown they can help address the knowledge gaps felt by many primary care providers. Legislation like the bipartisan Accelerating Access to Dementia and Alzheimer's Provider Training (AADAPT) Act (H.R. 3747) would expand access to high-quality virtual dementia education and training programs - addressing knowledge gaps, building workforce capacity, and empowering primary care providers to better diagnose and care for people living with Alzheimer's and other dementias. These programs are designed to be nimble, allowing new diagnostics and therapeutics - like recently approved blood-based biomarker tests - to be quickly integrated into training as they become available.

The *Alzheimer's Association's Dementia Care Practice Recommendations* include the following recommendations specific to 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, we know that 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, as well as their oversight of these activities. Training policies should be competency-based, should target providers in a broad range of settings and not 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.

Conclusion

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