



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

United States Senate Special Committee on Aging Hearing on “Uplifting Families, Workers, and Older Adults: Supporting Communities of Care”

March 9, 2023

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 “Uplifting Families, Workers, and Older Adults: Supporting Communities of Care.” 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. Among other issues, this statement highlights the value of long-term care settings as well as home- and community-based services (HCBS) for individuals living with Alzheimer's and other dementia.

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 6.5 million Americans age 65 and older are living with Alzheimer's dementia in 2022. In addition, total payments for all individuals with Alzheimer's or other dementias are estimated at \$321 billion (not including unpaid caregiving) in 2022. Medicare and Medicaid are expected to cover \$206 billion or 64% of the total health care and long-term care payments for people with Alzheimer's or other dementias. Total payments for health care, long-term care, and hospice care for people with Alzheimer's and other dementias are projected to increase to more than \$1.1 trillion in 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

We encourage the Committee to consider the following recommendations to improve 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.

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 is manageable. 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 HCBS. State governments can reduce long-term costs and increase access to person-centered care in the home and community settings including respite and adult day care, regardless of age or financial status through Medicaid and other state-supported programs.

Several states are implementing innovative solutions to address Alzheimer's in the Medicaid and non-Medicaid spaces by developing critical, cost-effective, dementia-specific HCBS programs. These programs are allowing people with dementia and their caregivers to access services and support that are uniquely tailored to meet their needs, allowing them to remain in their homes and communities longer and enjoy a greater quality of life. Medicaid should adopt a core set of home- and community-based services that are specifically designed for people with dementia. A core set of HCBS, in addition to other services, will allow people with Alzheimer's to continue to remain in their communities and be independent for as long as possible

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. Ten percent of adult day services specialize in caring for individuals with Alzheimer's disease or other dementias. The median cost of adult day services is \$75 per day, and the cost of adult day services has increased by 1.5 percent annually over the past five years.

Residential care facilities. Thirty-four percent of residents in residential care facilities, including assisted living facilities, have Alzheimer's or other dementias. Fifty-eight percent of residential care facilities offer programs for residents with dementia. The median cost of care in an assisted living facility is \$4,429 per month or \$53,148 per year, and the cost of assisted living has increased by 3.6 percent annually over the past five years.

Nursing home care. Forty-eight percent of nursing home residents have Alzheimer's or other dementias. Nursing home admission by age 80 is expected for 75 percent of people with dementia compared with only four percent of the general population. In all, an estimated two-thirds of those who die of dementia do so in nursing homes, compared with 20 percent of people with cancer and 28 percent of people dying from all other conditions. The average cost for a private room in a nursing home is \$299 per day (\$109,135 per year) and the average cost of a semi-private room is \$263 per day (\$95,995 per year). The cost of nursing home care has increased three percent annually over the past five years for both private and semi-private rooms.

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. We applaud Congress's passage of the Lifespan Respite Care Reauthorization Act (S. 995/H.R. 2035) to meet this demand.

Home- and Community-Based Services: 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. 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.

Caregivers for those living with Alzheimer's — usually family and friends — face substantial challenges. In 2021, more than 11 million unpaid caregivers provided an estimated 16 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economical value of over \$271.6 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 giving them an opportunity to manage and improve their own health.

Important provisions within recent legislation would add much-needed funds to home- and community-based services, permanently authorize protections against spousal impoverishment, and make permanent the Money Follows the Person program. Medicaid pays for long-term care services and nursing homes for some people with very low income and low assets, and the high use of these services by people with dementia translates into high costs to Medicaid. Average annual Medicaid payments per person for Medicare beneficiaries with Alzheimer's or other dementias are 23 times as great as average Medicaid payments for Medicare beneficiaries without Alzheimer's or other dementias. These important programs will help families and caregivers from becoming poverty-stricken in order for their loved ones to qualify for long-term care from Medicaid.

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 2023 Consolidated Appropriations Act (P.L. 117-328) 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.

Direct Care Workforce in Long-Term Care Settings

People living with Alzheimer's and other dementia make up a significant portion of all long-term care residents, comprising 48 percent of residents in nursing homes and 34 percent of all residents in assisted living communities and other residential care facilities. Twenty-four percent of Medicare beneficiaries with Alzheimer's or other dementias reside in a nursing home, compared with one percent of Medicare beneficiaries without these conditions. Approximately 75 percent of individuals with Alzheimer's disease diagnosed at age 70 will reside in a nursing home by age 80, compared with only four percent of the general population surviving to age 80. Given our constituents' intensive use of these services, the quality of this care is of the utmost importance.

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 per year. 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 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. 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 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.