



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

United States Senate Special Committee on Aging Hearing on "The Long-Term Care Workforce: Addressing Shortages and Improving the Profession"

April 16, 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 "**The Long-Term Care Workforce: Addressing Shortages and Improving the Profession**". 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. This statement highlights the importance of policies that will help ensure a quality healthcare workforce that can meet the needs of a growing aging population, including investments in direct care workers in long-term care settings, palliative and hospice care workers, and home- and community-based services workforce.

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 7 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 percent, 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.

Great progress has been made in advancing Alzheimer's and dementia research, providing hope to families in the midst of a terrible, fatal disease. And now that the Food and Drug Administration (FDA) has approved Alzheimer's treatments to slow progression at an early

stage, it's lifted that hope higher. However, people living with Alzheimer's and other dementia face unique health care challenges, and often primary care providers are the first clinicians with whom individuals discuss cognition concerns. Quality care delivered by trained providers leads to better health outcomes for individuals and caregivers and puts less strain on health systems. Yet, too often overburdened primary care providers are unable to access the latest patient-centered dementia training. Timely detection and accurate diagnosis of Alzheimer's or another dementia allows people to access medical, social, emotional, financial, and legal benefits sooner, and for patient and family preferences to drive health care decisions. Even though the vast majority of initial diagnoses are made by primary care physicians, nearly 40 percent reported that they were "never" or "only sometimes" comfortable making a diagnosis of Alzheimer's or another dementia. Moreover, findings from the Alzheimer's Association *2019 Alzheimer's Disease Facts and Figures* Special Report indicate that the vast majority of primary care physicians (94 percent) say it is important to assess all seniors for cognitive impairment, but they only report assessing, on average, about half of their patients.

And, the value of an accurate and early diagnosis cannot be ignored; it can significantly improve an individual's quality of life and could save up to \$231 billion in 2050 in medical and care costs. We encourage the Committee to consider the following recommendations to improve care for the growing number of families affected by Alzheimer's, especially given the unique challenges the dementia care workforce faces, like recruitment, retention, career advancement, regulation, and training.

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 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.

Given our constituents' intensive use of these services, the quality of this care is of the utmost importance. To this end, the Alzheimer's Association developed the *Alzheimer's Association's Dementia Care Practice Recommendations*. Grounded in the fundamentals of person-centered care and published in a special supplement of *The Gerontologist*, the Dementia Care Practice Recommendations outline recommendations for quality care practices based on a comprehensive review of current evidence, best practices, and expert opinion. The Dementia Care Practice Recommendations were developed to better define quality care across all settings, including assisted living, and throughout the disease course. They are intended for professional care providers who work with individuals living with dementia and their families in long-term and community-based care settings.

Assisted living communities should ensure that the care and services provided have a person-centered focus that includes: (1) **Knowing the person living with dementia.** The individual living with dementia is more than a diagnosis. It is important to know the unique and complete person including his/her values, beliefs, interests, abilities, likes and dislikes — both past and present. This information should inform every interaction and belief; (2) **Recognize and accept the person's reality.** It is important to see the world from the perspective of the individual living with dementia. Doing so recognizes behavior as a form of communication, thereby promoting effective and empathetic communication that validates feeling and connects with the individual and his/her reality; (3) **Identify and support ongoing opportunities for meaningful engagement.** Every experience and interaction can be seen as an opportunity for engagement. Engagement should be meaningful to, and purposeful for, the individual living with dementia. It should support interests and preferences, allow for choice and success, and recognize that even when the dementia is most severe, the person can experience joy, and comfort, and meaning in life; (4) **Create and maintain a supportive community for individuals, families and staff.** A supportive community allows for comfort and creates opportunities for success. It is a community that values each person and respects individual differences, celebrates accomplishments and occasions, and provides access to and opportunities for autonomy, engagement, and shared experiences; (5) **Evaluate care practices regularly and make appropriate changes.** It is important to regularly evaluate practices and models, share findings, and make changes to interactions, programs, and practices as needed. A culture of continuous quality improvement is a continuing theme throughout all of the recommendations.

An adequate and well-trained workforce is fundamental to providing quality dementia care. Assisted living communities should: (1) provide a thorough orientation program for new staff, as well as ongoing training; (2) develop systems for collecting and disseminating person-centered information; (3) encourage communication, teamwork, and interdepartmental/interdisciplinary collaboration; (4) establish an involved, care and supportive leadership team; (5) promote and encourage resident, staff, and family relationships; (5) evaluate systems and progress routinely for continuous improvement.

To maintain a strong dementia care workforce, assisted living communities should: (1) have staffing levels adequate to allow for proper care at all times — day and night; (2) ensure that all staff 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) ensure that staff have the opportunity for career growth. 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.

Last Congress, we were glad to support Chairman Casey's Innovation in Aging Act, S. 3473, which would invest in the research to evaluate the impact of the services provided by the aging services network on older adults' health and independence, such as long-term care and home-delivery meal programs. The Alzheimer's Association and AIM look forward to continuing working with the Committee this Congress to shape specific proposals to better train and support the direct care workforce. In the meantime, we encourage you to keep residents living with dementia top-of-mind as you continue this important work.

Expanding Capacity for Health Outcomes (Project ECHO)

We also ask that the Committee supports an expansion of the use of technology-enabled collaborative learning and capacity-building models, often referred to as Project ECHO. These education models can improve the capacity of providers, especially those in rural and underserved areas, on how to best meet the needs of all patients, including people living with Alzheimer's. In 2018, the Alzheimer's Association launched an Alzheimer's and Dementia Care Project ECHO Network – a highly successful telementoring program that has trained more than 330 health care professionals from 116 primary care practices and more than 250 professional care providers from 91 long-term care communities in a free continuing education series of interactive, case-based video conferencing sessions across the United States.

Project ECHO dementia models are helping primary care physicians in real-time understand how to use validated assessment tools appropriate for early and accurate diagnoses, educate families about the diagnosis and home management strategies, and help caregivers understand the behavioral changes associated with Alzheimer's. Project ECHO aims to improve health outcomes through a team-based approach while reducing geographic barriers and the cost of care. For example, the Alzheimer's Association's Alzheimer's and Dementia Care ECHO Program offers a free six-week telementoring program for professional care providers nationwide. Participants must be long-term care providers for people living with Alzheimer's or other dementia in long-term care settings. This dementia care training series is one of the first in the country focused on improving access to quality dementia care in the long-term setting. Each weekly session includes a short lesson on a particular aspect of dementia care, followed by a case discussion from a participating long-term care setting.

Participants express high levels of satisfaction with this program and the majority (95 percent) of primary care clinicians who participated in the Alzheimer's and Dementia Care ECHO program said the quality of care they provide improved as a result of their experience. Long-term and community-based care providers also benefit from Project ECHO dementia programs. Recent evaluations from the Alzheimer's Association demonstrate statistically meaningful increases in confidence in working with people living with dementia and overall disease knowledge post-ECHO completion and 92 percent of long-term care participants felt that the information gained through participation was valuable in their work.

In 2020, the Alzheimer's Association launched the Alzheimer's and Dementia Care ECHO Global Collaborative. We are engaging partners across the world using the ECHO model to increase equitable access to dementia detection and person-centered dementia care. This group meets quarterly and has identified three key working objectives: (1) increase the use of Project ECHO for Alzheimer's and other dementia care; (2) increase evidence around the efficacy of the ECHO model for dementia; and (3) increase and advance policy and funding support for ECHO programs focused on dementia. This robust network currently includes 18 partners spanning four continents, with nine additional organizations exploring the ECHO model for dementia.

One partner in the Alzheimer's and Dementia Care ECHO Global Collaborative is the Dementia ECHO, Indian Country Program is designed to support clinicians at the Indian Health Service (IHS) and caregivers to strengthen the knowledge and care around dementia tribal patients. These teleECHO programs are interactive online learning environments where clinicians and staff serving American Indian and Alaska Native patients connect with peers, engage in didactic presentations, collaborate on case consultations, and receive mentorship from clinical experts from across Indian Country. As a result, these ECHO programs enable primary care providers to better understand Alzheimer's and other forms of dementia and emphasize high-quality, person-centered care in community-based settings, and aim to improve health outcomes while reducing geographic barriers and the cost of care through a team-based approach.

Project ECHO was especially crucial during the COVID-19 pandemic, where the models played an important role in how health providers, public health officials, and scientists in real-time share best practices and information. For example, the Agency for Healthcare Research and Quality (AHRQ) established the AHRQ ECHO National Nursing Home COVID-19 Action Network of over 100 ECHO hubs to train nursing home staff on COVID testing, infection prevention, safety practices to protect residents and staff, quality improvement, and how to manage social isolation. The Network received nearly \$237 million in federal funding during the pandemic, and, as a result, was able to reach nearly two-thirds of nursing homes in the United States. Investing in Project ECHO models is an innovative way to improve the capacity of a quality healthcare workforce to meet the needs of a growing aging population, including primary care physicians, specialists, and long-term care workers.

The Alzheimer's Association and AIM are glad to support the Accelerating Access to Dementia and Alzheimer's Provider Training (AADAPT) Act, H.R. 7688, that would build upon the current Project ECHO program to provide grants specifically for Alzheimer's and dementia Project ECHOs to address the knowledge gaps and workforce capacity issues primary care providers face given the increasing population living with Alzheimer's disease and other dementia. We expect a companion bill to be introduced in the Senate soon and look forward to working with the members of the Committee on this important bipartisan legislation.

Quality Palliative and Hospice Care Workforce

There is also a need to expand the number of quality palliative and hospice care workers. We ask that the Committee supports the bipartisan Palliative Care and Hospice Education and Training Act (PCHETA) once it is reintroduced, which would ensure a high-quality palliative care and hospice workforce. Palliative and hospice care can improve both the quality of care and quality of life for those with advanced dementia. Nursing home residents with dementia who receive palliative care at the end of life, compared with those who do not receive such care, are up to 15 times less likely to die in a hospital, nearly 2.5 times less likely to have a hospitalization in the last 30 days of life, and up to 4.6 times less likely to have an emergency room visit in the last week of life. Individuals with advanced dementia who are enrolled in hospice have a lower rate of dying in the hospital, a lower rate of hospitalization in the last 30 days of life, and better symptom management. However, the availability and quality of palliative and hospice care are a concern. Less than half of surveyed nursing homes report having some sort of palliative care program. PCHETA would help ensure an adequate, well-trained palliative care workforce through workforce training, education and awareness, and enhanced research.

Home- and Community-Based Services Workforce

Expanded access to home- and community-based services (HCBS) is also crucial, and a strong HCBS workforce is needed to ensure quality care. People living with dementia make up a large proportion of all elderly people who use these important services. In fact, 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. For example, in-home care services, such as personal care services, companion services, or skilled care can allow those 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. Given the demands on and responsibilities of caregivers, respite services are also critical to their health and well-being, and may allow people with dementia to remain in their homes longer. We were glad to support Chairman Casey's Nursing Home Reform Modernization Act of 2021 last Congress, which would increase transparency, accountability, and oversight in nursing homes, improve staffing, and support innovation in the workforce structure of these facilities. We are grateful for the Committee's continued commitment to strengthening long-term care and bolstering the health care workforce, and we urge the Committee to continue to invest in the workforce through increased wages, benefits, and support. This is especially important as the majority of home care workers are disproportionately women of color.

Conclusion

The Alzheimer's Association and AIM appreciate the steadfast support of the Committee and its continued commitment to advancing legislation important to the millions of families affected by Alzheimer's and other dementia. We look forward to working with the Committee and other members of Congress in a bipartisan way to advance policies that will ensure a well-trained, adequate healthcare workforce, especially as the population of individuals living with dementia continues to grow.