

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

United States Senate Health, Education, Labor, and Pensions Committee Hearing on "Examining Health Care Workforce Shortages: Where Do We Go From Here?"

February 16, 2023

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Health, Education, Labor, and Pension Committee hearing on **"Examining Health Care Workforce Shortages: Where Do We Go From Here?"** 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 is able to 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 the 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.

An estimated 6.2 million Americans age 65 and older are living with Alzheimer's dementia in 2021. Total payments for all individuals with Alzheimer's or other dementias are estimated at \$355 billion (not including unpaid caregiving) in 2021. Medicare and Medicaid are expected to cover \$239 billion or 67 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.

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.

Expanding Capacity for Health Outcomes (Project ECHO)

First, we ask that you support 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. Participants express high levels of satisfaction with the program and the majority (95%) of primary care clinicians who join 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.

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. In the meantime, we encourage you to keep residents living with dementia top-of-mind as you continue this important work.

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. In fact, 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 remain supportive and enthusiastic about the work the Committee did last Congress around HCBS and we urge the Committee to continue to invest in strengthening the HCBS 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.