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

United States House Committee on Ways and Means Hearing on “Enhancing Access to Care at Home in Rural and Underserved Communities”
March 12, 2024

The Alzheimer’s Association and Alzheimer’s Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the United States House Committee on Ways and Means hearing on “Enhancing Access to Care at Home in Rural and Underserved Communities.” 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 emphasizes the importance of the preservation and expansion of telehealth in order to enhance access to care in rural and underserved communities.

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.

Expansion of Telehealth Service Coverage

The Alzheimer’s Association and AIM are grateful that the Centers for Medicare & Medicaid Services (CMS) permanently expanded Medicare and Medicaid coverage for many telehealth services important to persons living with dementia and caregivers. For example, CMS has permanently expanded coverage for numerous codes that are beneficial to people living with Alzheimer’s and other dementia so that they can continue accessing care in settings that best serve their unique needs. In particular, the Alzheimer’s Association and AIM supported CMS’s decision to allow for telehealth coverage of care planning CPT® code 99483. Care planning is critical for people with cognitive impairment under normal circumstances to help them manage comorbid conditions and make decisions about long-term care and support services, among others. Ensuring that a plan is established, documented, and updated is now more important than ever. Making this service available via telehealth will improve access to care planning for this vulnerable population. To that end, we also thank Congress for passing the bipartisan Improving HOPE for Alzheimer’s Act (P.L. 116-260), which continues to educate clinicians on the importance and availability of this crucial Medicare care planning service.
Finally, we appreciate CMS’s flexibility in allowing telehealth technology to be used in home health delivery. Thirty-two percent of individuals using home health services have Alzheimer’s or other dementia. The ability to receive care in the home decreases visits to unfamiliar places that may cause agitation in people with dementia and can ease some burden on caregivers. Additionally, it provides a sustained option for care for people in rural areas with medical deserts. They now have reduced barriers to care, which helps both people living with Alzheimer’s and other dementias and their families and caregivers. This increased flexibility can reduce interruptions in access to quality health care.

**Expanding Capacity for Health Outcomes (Project ECHO)**

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. First, we ask that the Committee recognize the importance of the expansion of and continued investment in the use of technology-enabled collaborative learning and capacity-building models, often referred to as Project ECHO. These models use a hub-and-spoke approach by virtually 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, frontier, and underserved areas, on how to best meet the needs of people living with Alzheimer’s and other dementia. 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 450 health care professionals from 170 primary care practices and more than 350 professional care providers from 140 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 percent) 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. The Indian Country Program is designed to support clinicians at the Indian Health Service and caregivers to strengthen the knowledge and care around dementia tribal patients. These ECHO 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.

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 (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. As a result, these ECHO programs enable primary care providers to better understand Alzheimer’s and other forms of dementia, 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. 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.

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 diseases such as 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 in rural, frontier, and underserved areas that would help people living with Alzheimer’s and other dementia receive consistent, high-quality health care.