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

United States House Committee on Energy and Commerce, Health Subcommittee
Legislative Hearing on Checking-In on CMMI: Assessing the Transition to Value-Based Care

June 13, 2024

The Alzheimer’s Association and Alzheimer’s Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the House Energy and Commerce, Health Subcommittee hearing on "Checking-In on CMMI: Assessing the Transition to Value-Based Care." We are grateful to the Subcommittee and CMMI for leading and implementing policies that improve the lives of people living with dementia and their families.

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.

Millions of Americans living with dementia often face the challenge of navigating complex care landscapes without adequate support, leading to poorer health outcomes, high rates of hospitalization, and significant caregiver stress. According to the Alzheimer’s Association’s 2024 Facts and Figures and Special Report, nearly 7 million Americans are living with Alzheimer’s. By 2050, that number will approach 13 million. Sixty percent of health care workers believe that the U.S. health care system is not effectively helping patients and their families navigate dementia care. A majority of caregivers (70 percent) report that coordinating care is stressful, and two in three (66 percent) have difficulty finding resources and support for their needs. Unfortunately, our work is only growing more urgent.

Importance of Value-Based Care

Caring for an individual living with dementia involves many unique and often challenging elements. Dementia care management is a model of care that enables individuals living with Alzheimer’s and their caregivers to more seamlessly navigate the health care and social support systems and obtain more timely access to care. Last year, the Centers for Medicare & Medicaid Services (CMS) announced a new alternative payment model, the Guiding an Improved Dementia Experience (GUIDE) Model. This announcement was made after Alzheimer’s
advocates and bipartisan congressional champions had been growing support in Congress for the bipartisan Comprehensive Care for Alzheimer’s Act (H.R. 1637 / S. 626). The GUIDE model will begin on July 1, 2024, through the Center for Medicare and Medicaid Innovation (CMMI), and will focus on providing key supportive services to people with dementia, including comprehensive, person-centered assessments and care plans, care coordination, and 24/7 access to a support line. People living with dementia and their caregivers will also have access to a care navigator who will help them access services and support.

In addition, the model will help people with dementia and their caregivers access education and support by providing a link between the clinical health care system and community-based providers. Model participants will help caregivers access respite services, which enable them to take temporary breaks from their caregiving responsibilities.

The initiative will continue to work to improve the health outcomes and caregiving experience of underrepresented individuals and their families through increased access to specialty dementia care. The GUIDE Model will provide financial and technical assistance for developing new dementia care programs targeted to underserved areas.

Addressing the Gap in Dementia Care for Individuals and Caregivers

The Dementia Care Navigation Service (DCNS), powered by Rippl and the Alzheimer’s Association, leverages Rippl’s proven model of on-demand dementia care and the extensive resources of the Alzheimer’s Association, including its 24/7 Helpline and community education programs. Later this year, the service will roll out across the nation through both public and private payers, delivering the gold standard of dementia care to thousands of individuals and their caregivers who otherwise do not have access to the comprehensive care they desperately need. The DCNS has been approved by CMS to participate in the eight-year GUIDE Model pilot program.

Preparing the Dementia Workforce

People with Alzheimer’s and other dementias receive care and support from a wide variety of health and long-term care professionals. But, the medical, psychological, and social care needs of those living with dementia often make care delivery challenging and more demanding than for those with other health conditions. As our nation ages and the demand for such care increases, more must be done to ensure an adequately trained workforce.

Today, only half of those living with Alzheimer’s disease are diagnosed, and of those, only half are told of their diagnoses. In 85 percent of cases, the initial diagnosis of Alzheimer’s is made by a non-dementia specialist — usually a primary care provider. Overburdened primary care providers are too often unable to access the latest patient-centered dementia training.
Project ECHO programs, which are virtual continuing education programs for health care providers, have shown they can help address the knowledge gaps felt by many primary care providers and reach rural and medically underserved areas where primary care physicians are especially strained.

Through the use of Project ECHO, the Accelerating Access to Dementia & Alzheimer’s Provider Training (AADAPT) Act (H.R. 7688 / S. 4276) would provide virtual Alzheimer’s and dementia education and training to more primary care providers to help them better detect, diagnose, care, and treat Alzheimer’s and other forms of dementia. The bipartisan bill would expand the current ECHO program to provide grants specifically for Alzheimer’s and dementia to address the knowledge gaps and workforce capacity issues primary care providers face.

Conclusion

The Alzheimer’s Association and AIM appreciate the Subcommittee’s steadfast support and continued commitment to issues important to the millions of families affected by Alzheimer’s and related dementias. We would be glad to serve as a resource to the Subcommittee as they monitor these important issues and how they relate to individuals living with Alzheimer’s and related dementias.