

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

United States House Committee on Energy and Commerce Hearing on "Addressing the Urgent Needs of Our Tribal Communities"

July 8, 2020

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the House Committee on Energy and Commerce hearing entitled "Addressing the Urgent Needs of Our Tribal Communities." The Association and AIM thank the Committee for focusing on this important issue, especially as the impact of Alzheimer's and other dementia continues to grow in tribal communities. This statement provides an overview of policies that would help address Alzheimer's and other dementia in Indian Country, including targeted public health strategies and alignment with the *National Plan to Address Alzheimer's Disease*.

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 sister organization, working in 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 development of approaches to reduce the risk of developing dementia.

Public Health Approach to Addressing Alzheimer's in Tribal Communities

The population of older American Indians and Alaska Natives (AI/ANs) is growing — and quickly. Since Alzheimer's and other dementia is more common with advanced age, as the AI/AN older adult population grows, so will the impact of cognitive impairment. Between 2014–2060, the number of AI/ANs aged 65 and older living with dementia is projected to grow over five times.¹ This population will progressively depend on caregivers and community resources as they become less able to care for themselves. In addition to the suffering caused by the disease, however, Alzheimer's is also creating an enormous strain on the health care system, families, and federal and tribal budgets.

Tribal leaders can build on strengths in their cultures and traditions, which provide unique opportunities to improve the lives of older adults living with dementia and to support their families and communities. The Centers for Disease Control and Prevention's (CDC) [Healthy Brain Initiative's Road Map for Indian Country](#) was created with input from experts, tribal leaders, and elders throughout Indian Country. This Road Map aims to help tribal community leaders

¹ Matthews K, Xu W, Gaglioti A, Holt J, Croft J, Mack D, McGuire L. (2019). Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged ≥65 years. *Alzheimer's Dement.* 15(1),17-24.

understand how dementia and associated caregiving is affecting their community and then consider what approaches, including public health strategies, to implement. Among many findings, the Road Map discussions revealed that Alzheimer's and related cognitive health issues are viewed as a serious and growing problem that should be approached with sensitivity to unique social, economic, historical, and cultural attributes of AI/ANs. The approaches need to be tailored for existing tribal health systems and integrated into public health efforts.

Investing in a targeted Alzheimer's public health response in Indian Country will help create population-level improvements, achieve a higher quality of life for those living with the disease and their caregivers, and reduce associated costs. In 2018, Congress acted decisively to address Alzheimer's as a growing public health issue through the passage of the BOLD Infrastructure for Alzheimer's Act (P.L. 115-406). This strong bipartisan law authorizes \$100 million over five years for the CDC to build a robust Alzheimer's public health infrastructure across the country. Importantly, the law includes a focus on tribal communities through the establishment of Alzheimer's and Related Dementias Public Health Centers of Excellence and funding for public health departments to increase early detection and diagnosis, reduce risk, prevent avoidable hospitalizations, reduce health disparities, support the needs of caregivers, and provide care planning for people living with the disease. These important public health actions can allow AI/ANs with Alzheimer's to live in their homes longer and delay costly long-term nursing home care. We urge the Committee and Congress to fully fund BOLD's implementation by providing \$20 million to CDC for these efforts in FY21.

An integrated approach to Alzheimer's and related dementias activities at the Indian Health Service (IHS) also benefits AI/ANs. We urge the Committee and Congress to provide increased funding for IHS efforts to support this particularly vulnerable population. Specifically, we support \$1 million for Alzheimer's awareness campaigns tailored for the Indian perspective to increase recognition of early signs of Alzheimer's and other dementias and when to consult a physician. Only 31 percent of older AI/ANs who experience memory loss have talked with their healthcare provider about it. We also support \$2 million for the development of quarterly, competency-based training curriculum for primary care practitioners to ensure a core competency on assessing, diagnosing, and managing individuals with Alzheimer's and other dementias. These quarterly trainings could be in-person or virtually through the use of technology-based collaborative learning and capacity building models, such as Project ECHO. We also urge Congress to provide \$2 million for five pilot programs to increase early detection and accurate diagnosis, including evidence-based caregiver services within Indian Country. IHS could work with the Health Resources and Services Administration in the development of this training curriculum. Finally, we support \$500,000 for an annual report to the Congressional Committees of jurisdiction and the Advisory Council on Alzheimer's Research, Care, and Services with data elements including the prevalence of Alzheimer's in AI/ANs, incidence in the preceding year, and access to services. This data will help identify opportunities for public health interventions and enable state and federal policymakers to make informed decisions when developing plans and policies.

National Plan to Address Alzheimer's Disease

Supporting Tribal communities and improving their access to quality dementia care and resources features prominently throughout the Department of Health and Human Services's *National Plan to Address Alzheimer's Disease*, the country's strategic plan to combat the Alzheimer's crisis. IHS and other stakeholders are driving action items to strengthen the ability of primary care teams in Indian Country to meet the needs of people with Alzheimer's disease and related dementias and their caregivers, to increase awareness of dementia in tribal and urban Indian communities and of the availability of services, and to increase awareness of the importance of brain health for tribal communities in culturally-sensitive ways. We urge the Committee to align its efforts with relevant action items in the National Plan.

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. The number of older AI/ANs living with dementia is projected to increase greatly over the next few decades. We look forward to working with the Committee and other members of Congress in a bipartisan way to advance policies that would help address Alzheimer's and other dementia in Indian Country, including targeted public health strategies and alignment with the *National Plan to Address Alzheimer's Disease*.