

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

United States House Committee on Energy and Commerce, Subcommittee on Health Hearing on "Health Care Inequality: Confronting Racial and Ethnic Disparities in COVID-19 and the Health Care System"

June 17, 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, Subcommittee on Health hearing entitled "Health Care Inequality: Confronting Racial and Ethnic Disparities in COVID-19 and the Health Care System." The Association and AIM thank the Subcommittee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers. This statement provides an overview of how Alzheimer's and other dementia disproportionately affect diverse communities and how COVID-19 exacerbates existing health disparities.

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.

COVID-19 Impact on Health Disparities

The Alzheimer's Association is committed to the inclusion of all communities and the advancement of health equity through conversations, work, and partnerships. The COVID-19 pandemic has further exposed health differences that exist between racial and ethnic groups due to economic and social conditions. During public health emergencies, these conditions can isolate people from the resources needed to prepare and keep their families safe.

Alzheimer's and other dementia disproportionately affect older blacks/African Americans and Hispanics/Latinos than older whites. Black/African Americans are two to three times more likely to develop Alzheimer's than whites, and Hispanics/Latinos are one to two times more likely to develop Alzheimer's than whites. In addition, people living with Alzheimer's and other dementia are at increased risk of having serious complications relating to COVID-19 due to their typical age and likelihood of coexisting conditions.

A higher prevalence of Alzheimer's and dementia among blacks/African Americans and Hispanics/Latinos can also mean a higher likelihood of living in long-term care facilities, resulting

in greater exposure to COVID-19. Across the country these facilities, their staff, and their residents are experiencing a crisis due to a lack of transparency, an inability to access the necessary testing, inaccurate reporting, and more. The Alzheimer's Association and AIM have released policy recommendations, [Improving the State and Federal Response to COVID-19 in Long-Term Care Settings](#), to increase testing, reporting, surge activation, and provide urgent support, like access to personal protective equipment (PPE). It is important that data on race and ethnicity are also included in the required reporting, and that data is made publicly available. This will be especially important in ensuring preparedness and targeted support for a potential second wave of COVID-19.

A range of behavioral, social, economic, and environmental determinants influence health status and these health determinants are heightening the impact of the COVID-19 crisis on diverse racial and ethnic populations. For example, blacks/African Americans and Hispanics/Latinos are more likely than whites to experience poverty and discrimination and receive lower-quality healthcare and education which contribute to disparities in health, including cognitive health. Poor diets and malnutrition are also associated with cognitive impairment. We urge the Subcommittee to advance policies to better understand and adequately respond to the determinants that create and sustain these disparities.

Health Disparities in Research

It is also critical to note that while the field of Alzheimer's biomedical research has made great gains over the years in understanding the brain changes associated with the disease and how the disease progresses, much of the research to date has not included sufficient numbers of blacks/African Americans, Hispanics/Latinos, Asian Americans/Pacific Islanders, and Native Americans to be representative of the U.S. population. Moreover, because blacks/African Americans and Hispanics/Latinos are at increased risk for Alzheimer's, the underrepresentation of these populations hampers the conduct of rigorous research to understand these health disparities. Additional research involving individuals from underrepresented ethnic and racial groups is necessary to gain a comprehensive understanding of Alzheimer's and other dementia in the U.S. It is important that this research incorporate environmental, sociocultural, and behavioral determinants to more fully understand these disparities. This is consistent with the National Institute on Aging's *NIA Health Disparities Research Framework*.

In order to increase the recruitment and retention of diverse populations in clinical trials, researchers must understand how to foster and maintain partnerships with trusted community-based organizations, ensure that members of their research team reflect underrepresented groups, and budget adequately for recruitment and retention efforts. Clinicians and researchers must also be able to implement culturally appropriate research methodologies across different ethnorracial groups.

Additionally, accurate diagnoses are critical to better understanding and addressing disparities, yet the tests currently used to measure cognition are not sensitive to the impact of education and culture, resulting in incomplete and inaccurate data on cognitive impairment and decline in diverse

individuals. Validated tools to capture these impacts are needed, as is training for clinicians who work with racially and ethnically diverse populations.

Finally, efforts to address health disparities must also include caregivers since they are often an integral part of their loved ones' participation in research and clinical trials. Developing and disseminating relevant educational materials specific to caregivers from diverse groups is important and these caregivers must be included in scientific inquiries addressing caregiver and family needs.

Conclusion

The Alzheimer's Association and AIM appreciate the steadfast support of the Subcommittee 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 Subcommittee, Committee, and other members of Congress in a bipartisan way to advance policies that would help address the longstanding health disparities in the Alzheimer's and other dementia community, both during the COVID-19 pandemic and beyond.