

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

United States Senate Committee on Health, Education, Labor and Pensions (HELP) Hearing on "COVID-19: An Update on the Federal Response"

September 23, 2020

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Committee on Health, Education, Labor and Pensions (HELP) hearing entitled "COVID-19: An Update on the Federal Response." 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 provides an overview of urgent policies that are needed now to protect this vulnerable population during the COVID-19 pandemic and beyond, including actions in long-term and community-based care settings, a focus on reducing health disparities, and efforts to expand capacity for health outcomes through Project ECHO.

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 Long-Term Care

Nursing homes and assisted living communities are on the frontlines of the COVID-19 crisis, where 48 percent of nursing home residents are living with dementia, and 42 percent of residents in residential care facilities have Alzheimer's or another dementia. Residents with dementia are particularly susceptible to COVID-19 due to their typical age, their significantly increased likelihood of coexisting chronic conditions, and the community nature of long-term care settings. 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. According to some reports, nearly 70,000 residents and employees of nursing homes and long-term care facilities have died, representing more than 40 percent of the total death toll in the United States.

The Alzheimer's Association released policy recommendations, [*Improving the State and Federal Response to COVID-19 in Long-Term Care Settings*](#), to address both the immediate and long-term issues impacting these settings during the COVID-19 pandemic. These recommendations focus on four main areas: enhancing rapid, point-of-care testing in long-term care community settings; implementing timely reporting; developing protocols to respond to a

rise in cases; and ensuring all facilities have necessary support, like personal protective equipment (PPE) and televisitation services.

It is absolutely imperative that each nursing home and residential care community have the onsite testing capability to verify that all residents, staff, and visitors are free of COVID-19 infection, whether or not they are symptomatic. We appreciate the Administration's recent purchase of 150 million rapid tests, a portion of which we expect will be directed to long-term care settings. We also appreciate the recent announcement by the Centers for Medicare & Medicaid Services (CMS) that certain nursing home workers should receive testing as frequently as twice a week. We also note the recent release of recommendations from the Coronavirus Commission for Safety and Quality in Nursing Homes, convened by CMS and facilitated by MITRE Corporation. However these actions and recommendations still fall short of what is urgently needed to protect the vulnerable Americans living in long-term care communities. We continue to advocate for the "White House Standard" of daily rapid-response testing for all new individuals who come onsite, and retesting for returning individuals who enter the facility, in accordance with local guidance. We also support the immediate and accurate reporting of long-term care COVID-19 cases. These reports should be updated upon remission, death, transfer, or other appropriate status update. With all appropriate privacy safeguards for individuals, this reported data should be freely and immediately accessible to everyone, down to the facility level. Any reported cases should trigger careful, ongoing monitoring and, if conditions warrant, "strike teams" should be deployed to provide needed support until the outbreak is appropriately contained and eliminated. It is also essential that all nursing homes and residential living communities have full, timely access to all needed PPE, testing equipment, training, and external support to keep them COVID-19-free. Importantly, this includes requiring these settings to address social isolation and ensure people with Alzheimer's and other dementia are able to communicate with their family and friends. Many other institutions ranging from the White House to the Big Ten, NBA, and NFL have recognized the importance of testing and have committed to rigorous protocols to ensure the safety of its athletes. We must do the same for our citizens living in long-term care.

COVID-19 Impact on Health Disparities

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. It is crucial that nursing homes and residential living communities include data on race and ethnicity in their reporting, and that the data is made publicly available on a timely basis. This will be especially important in ensuring preparedness and targeted support for a potential second wave of COVID-19 or other future pandemic.

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 Committee to advance policies to better understand and adequately respond to the determinants that create and sustain these health disparities.

Expanding Capacity for Health Outcomes (Project ECHO)

Finally, we ask that you support provisions to expand the use of technology-enabled collaborative learning and capacity-building models. These education models, often referred to as Project ECHO, can improve the capacity of providers, especially those in rural and underserved areas, on how to best meet the needs of people living with Alzheimer's. During the COVID-19 pandemic, Project ECHO is helping primary care physicians in real-time understand how to use validated assessment tools appropriate for virtual use to make early and accurate diagnoses, educate families about the diagnosis and home management strategies, and help caregivers understand the behavioral changes associated with Alzheimer's, which can be heightened during isolation. Project ECHO is also helping long-term care providers understand in real-time how to train temporary staff that may not be familiar with how to best care for people with Alzheimer's, implement important health strategies such as hand-washing and social distancing for people with Alzheimer's, and effectively communicate with residents to help them understand the COVID-19 pandemic. In fact, the Alzheimer's Association developed a special topic [Project ECHO](#) dementia series to help assisted living communities during COVID-19 based on our guidelines, [Emergency Preparedness: Caring for persons living with dementia in a long-term or community-based care setting](#).

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. However, our nation has not done enough to support Americans living in long-term communities during the COVID-19 pandemic. We urge the Committee and other members of Congress to work in a bipartisan way to advance policies that will help protect this vulnerable population during the COVID-19 pandemic and beyond, including actions for the long-term care community, a focus on reducing health disparities, and efforts to expand capacity for health outcomes through Project ECHO.