



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

### **Healthy Future Task Force Security Subcommittee Request For Information on Pandemic Preparedness, Public Health, and Supply Chains and Medical Independence from China**

**January 31, 2022**

On behalf of the Alzheimer's Association and the Alzheimer's Impact Movement (AIM), including our nationwide network of advocates, thank you for your continued bipartisan leadership on issues important to Americans living with Alzheimer's and other dementias, and their caregivers. The Alzheimer's Association and AIM appreciate the opportunity to provide input in response to the Subcommittee's request for feedback on policies within the Subcommittee's jurisdiction.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. It is the nonprofit with the highest impact in Alzheimer's research worldwide and is committed to accelerating research toward methods of treatment, prevention, and, ultimately, a cure. AIM is the advocacy affiliate of the Alzheimer's Association, 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.

#### **Pandemic Preparedness**

At least 184,000 residents and employees of nursing homes and long-term care facilities have died from COVID-19, representing over 30 percent of the total death toll in the United States. These 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.

These challenges are compounded by the negative consequences of social isolation that many older adults already experience. Social isolation is an issue within the aging community as a whole, exacerbated due to the current pandemic, and acutely impacting those living with Alzheimer's and other dementia.

#### **Long-Term and Community-Based Care Policies**

To best support individuals living with Alzheimer's and dementia during the COVID-19 pandemic, the Alzheimer's Association released a comprehensive set of long-term care policy recommendations for federal and state lawmakers, [\*Improving the State and Federal Response to COVID-19 in Long-Term Care Settings\*](#). These recommendations focus on four areas: (1) rapid point-of-care testing, (2) reporting, (3) surge activation, and (4) providing support.

Dedicated funding for testing and tracing in nursing homes and assisted living communities is crucial. All cases of COVID-19 in these settings need to be reported immediately and accurately. 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 all down to the facility level. It is critical that data on race and ethnicity are included in this reporting, which will be especially important in ensuring targeted support for the entirety of the COVID-19 pandemic, and preparedness for potential future pandemics.

As “hot spots” occur, they must be dealt with urgently and effectively. Any reported COVID-19 cases should trigger careful, ongoing monitoring and, if conditions warrant, well-trained and equipped strike teams should be deployed to the facility to provide needed support until the outbreak is contained and eliminated. All nursing homes and assisted living communities must have full access to all needed personal protective equipment (PPE), testing equipment, training, and external support to keep them COVID-19-free. It is also important to ensure increased access to televisitiation technologies to address social isolation in long-term care settings, which can have a devastating impact, so that people living with dementia are able to continue communicating with designated family and friends.

These policies are designed to create a strong and decisive response to the COVID-19 crisis in all long-term care settings and we were grateful to see many of them enacted as part of the American Rescue Plan Act of 2021 (P.L. 117-2). We thank you for your work to ensure these critical provisions were included, as they represent a significant step forward in improving care during this pandemic and beyond.

In addition, with the approval of multiple safe and effective vaccines and boosters, we urge the continued prioritization of access for Americans over the age of 65, particularly those in long-term care settings. This is consistent with the Centers for Disease Control and Prevention's recommendation that long-term care residents be prioritized for access to vaccines, as well as the health care workers caring for some of the most vulnerable in our country and who provide an enormous service to society as a whole.

Lastly, expanded access to home- and community-based services (HCBS) is crucial, and a strong HCBS workforce is needed to ensure quality care. People living with dementia make up a large proportion of all elderly people who use these important services. In fact, 31 percent of individuals using adult day services have dementia. Access to these services can help people with dementia live in their homes longer and improve quality of life for both themselves and their caregivers. For example, in-home care services, such as personal care services, companion services, or skilled care can allow those living with dementia to stay in familiar environments and be of considerable assistance to caregivers. Adult day services can provide social engagement and assistance with daily activities. Given the demands on and responsibilities of caregivers, respite services are also critical to their health and well-being, and may allow people with dementia to remain in their homes longer. Strengthening the HCBS workforce through increased

wages, benefits, and support is also especially important as the majority of home care workers are women of color.

### Improved Response Coordination

There is also a need for greater coordination between federal, state, and local officials. We believe that there must be clear lines of responsibility between federal, state, and local offices during public health emergencies. Congress must clarify who is in charge and these roles and responsibilities must also be clearly communicated to states and local governments so they can include this information in their own preparedness planning.

The Alzheimer's Association and AIM recommend that each state designate one specific point person on long-term care issues to liaise with the federal government in a time of crisis. Oversight for separate long-term care settings falls to different federal and state agencies which can make it difficult to coordinate efficiently during a pandemic. If states were to establish one long-term care point person in charge of communicating with the federal government during times of crises, it would lead to a more coordinated, tailored response in long-term care communities.

Improved federal and state response coordination would also help ensure sufficient stockpiling and equitable distribution chains of essential testing, PPE, and vaccines, when available. These supplies and distribution chains should also include caregivers and home- and community-based care providers.

### Telehealth Access

The Alzheimer's Association and AIM also support the expansion of Medicare and Medicaid coverage for certain telehealth services in response to the COVID-19 pandemic. The Centers for Medicare & Medicaid Services (CMS) has permanently expanded coverage for numerous codes that are beneficial to people living with Alzheimer's and other dementia. This population is particularly vulnerable to the effects of COVID-19 due to their typical age and their co-occurring chronic conditions, so we appreciate the flexibilities CMS has implemented to reduce the risk of their exposure to the virus and ensure regular access to quality care.

The Alzheimer's Association and AIM particularly support 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* (S. 880/H.R. 1873), which is educating 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. This increased flexibility can reduce interruptions in access to this kind of quality care. We also support CMS's expansion of the licensed practitioners, such as nurse practitioners and physician assistants, who can order Medicaid home health services. Twenty-seven percent of older individuals with Alzheimer's or other dementia who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without dementia.

## **Public Health**

Public health professionals play a critical role in minimizing the negative impacts of pandemics like COVID-19. Public health officials are able to tailor the federal, state, and local response in order to address the special vulnerabilities of people living with Alzheimer's, and their caregivers. During a pandemic this not only saves lives, but also protects the larger community and may reduce strain on health care systems.

The Alzheimer's Association and AIM recommend that each state public health department have an internal expert with deep knowledge of the unique needs of people living with Alzheimer's and other dementia. This expert should be responsible for improving the current COVID-19 response and shaping future emergency preparedness plans and providing better guidance to local health departments. The lack of a senior career staff director with expertise in Alzheimer's and other dementia in many state public health departments has affected the ability of those departments to effectively tailor the COVID-19 emergency response for those with cognitive impairment.

We also recommend that the Centers for Disease Control and Prevention (CDC) ensure there is a full-time gerontologist or geriatrician within the Infectious Disease National Centers who is able to liaise on emergency preparedness and response. This will help ensure readiness in how to respond to the unique needs of seniors and people with Alzheimer's and other dementia when a new threat arises. CDC should also update its 2012 cross-sector guide for states and communities on "*Identifying Vulnerable Older Adults and Legal Options for Increasing Their Protection During All-Hazards Emergencies.*"

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

The Alzheimer's Association and AIM are thankful for the inclusion of language in the Consolidated Appropriations Act, 2021 (P.L. 116-260) to expand the use of technology-enabled collaborative learning and capacity-building models. These innovative education models, often referred to as Project ECHO, help build workforce capacity and improve access to care. These models use a hub-and-spoke approach by 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 and underserved areas, on how to best meet the needs of people living with Alzheimer's and other dementia.

Project ECHO continues to play an important role in how health providers, public health officials, and scientists are sharing best practices and information for addressing the COVID-19 pandemic. [Project ECHO](#) dementia models are 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 social isolation. Project ECHO is also helping long-term care providers in real-time understand 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, using funds from the Provider Relief Fund established by the Coronavirus Aid, Relief, and Economic Security (CARES) Act (P.L. 116-136), the Agency for Healthcare Research and Quality (AHRQ) established the AHRQ ECHO National Nursing Home COVID-19 Action 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 Alzheimer's Association was an approved Training Center, engaging 348 nursing homes/42,496 licensed beds in 267 sessions during the 35-week initiative.

Beyond the COVID-19 pandemic, the Alzheimer's Association has conducted multiple Project ECHO programs in primary care and assisted living communities. These Project ECHO models focus on increasing access to dementia diagnoses and care through primary care providers and on increasing person-centered dementia care in assisted living communities. According to an evaluation of the Association's first two pilot programs by the Center for Evaluation and Applied Research at The New York Academy of Medicine, primary care participants reported the most significant knowledge gains in identifying and screening for dementia, medication management, and communication with patients and family members. The evaluation also showed that participants from assisted living communities said the increased knowledge led to a change in their practices and gave them a better understanding of person-centered care.

The Alzheimer's Association is also formalizing a global network of ECHO hubs to address Alzheimer's and other dementia, and will build momentum for additional ECHO hub creation by partnering with the research community, medical professionals, key stakeholders in the dementia care industry, and policy leaders and advocates. This consortium of thought leaders across the spectrum will increase evidence around the use of ECHO in promoting best practice dementia care, accelerate the uptake of evidence into practice, and help policymakers understand and support Project ECHO dementia models.

### Emergency Preparedness

Emergency situations, such as the current COVID-19 pandemic, present special challenges to the delivery of Alzheimer's and dementia care in long-term and community-based care settings, including nursing homes, assisted living, home health, home care, and adult day care.

Employees can also be affected in emergencies. Maintaining operations with the expected staffing shortages during any pandemic, epidemic, or disaster can be very difficult. During this time, non-clinical staff may be needed to assist with care.

The Alzheimer's Association and AIM have released [COVID-19 Tips for Caregivers in Long-Term or Community-Based Care Settings](#) to ensure delivery of person-centered care by helping professionals respond quickly and appropriately to people living with dementia. These guidelines are grounded in the Association's evidence-based [Dementia Care Practice Recommendations](#).

### Addressing 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 Black and Hispanic Americans compared to older White Americans. Black Americans are about twice as likely to develop Alzheimer's and Hispanic Americans are about one and a half times more likely to develop the disease. However, much of the Alzheimer's research to date has not included sufficient numbers of Blacks, Hispanics, Asian Americans/Pacific Islanders, and Native Americans to be representative of the U.S. population. The underrepresentation of these populations not only hinders the ability of researchers to understand these health disparities, it also restricts their knowledge of how an approved therapy or diagnostic may affect the population most likely to need the treatment. There is therefore an urgent need for current and future research to include increased numbers of Blacks, Hispanics, Asian Americans/Pacific Islanders, and Native Americans in clinical trials to ensure everyone benefits from advances in Alzheimer's science.

According to the [Alzheimer's Association 2021 Alzheimer's Disease Facts and Figures special report](#), nearly two-thirds of Black Americans (62%) believe medical research is biased against people of color — a view shared by substantial numbers of Asian Americans (45%), Native Americans (40%), and Hispanic Americans (36%). In fact, only half of Black Americans (53%) trust a future cure for Alzheimer's will be shared equally regardless of race, color, or ethnicity. This underscores the need to build and restore trust in underrepresented communities. Strong community relationships can serve to address misconceptions and mistrust about research because the community has a sense of ownership in the research initiative. Community-based participatory research and engagement with community-based organizations are two strategies that can accomplish this goal.

### **Currently Available Resources**

The Alzheimer's Association currently provides numerous resources and supports as people with mild cognitive impairment, Alzheimer's disease, or other dementia and their families look to make financial decisions. The Association runs a 24/7 Helpline staffed by specialists and master's-level clinicians to offer confidential support and information to people living with

dementia, caregivers, families, and the public. Additionally, The Association and AARP partnered for a community resource finder which is available at [alz.org/CRF](http://alz.org/CRF).

### **Conclusion**

Again, we thank the Subcommittee for the opportunity to provide input on these critical topics, particularly given their impact on the Alzheimer's and dementia community. We appreciate the Subcommittee's commitment to these issues, and look forward to working with you and other members of Congress on issues important to Americans living with Alzheimer's and other dementias, their families, and caregivers.