

**Alzheimer's Association and Alzheimer's Impact Movement Response to United States  
Senate Committee on Health, Education, Labor and Pensions (HELP)  
Request for Stakeholder Input on Workforce Development Policy Ideas**

**April 9, 2021**

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this response to the Senate Committee on Health, Education, Labor and Pensions (HELP)'s request for stakeholder input on workforce development policy ideas. 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 policies that will help expand the capacity of a quality healthcare workforce to meet the needs of a growing aging population, including investments in direct care workers in long-term care settings, palliative and hospice care workers, home and community-based services workforce, and Project ECHO models.

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 arm, 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.

**Direct Care Workforce in Long-term Care Settings**

The direct care workforce within long-term care settings is expanding rapidly: it grew by half within a decade, from 3 million workers in 2009 to almost 4.6 million in 2019.<sup>1</sup> As the United States population ages, the long-term care sector is expected to add a further 1.3 million direct care jobs from 2018 to 2028 — more new jobs than any other occupation in the U.S. economy.<sup>2</sup> By 2030, 3.4 million more direct care workers will be needed — a 48% increase from 2015.<sup>3</sup>

The growing number of people living with dementia will contribute to the demand for these workers: By 2060, the number of people age 65 and older with Alzheimer's dementia is projected to reach 13.8 million, and between 2020 and 2025 every state across the country is expected to experience an increase of at least 6.7 percent in the number of people with Alzheimer's.<sup>4</sup> Shortages in direct care workers will place an even bigger burden on family and friends who provide unpaid care — already an effort equivalent to nearly \$257 billion per year.<sup>5</sup> Finally, the

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<sup>1</sup> PHI. (2021). *Caring for the Future: The Power and Potential of America's Direct Care Workforce*.

<sup>2</sup> Ibid.

<sup>3</sup> Alzheimer's Impact Movement. (2021). Fact Sheet: Dementia-Capable Workforce.

<sup>4</sup> Alzheimer's Association. (2021). *2021 Alzheimer's Disease Facts and Figures*.

<sup>5</sup> Ibid.

COVID-19 pandemic brought into sharp focus the critical contribution these workers make to our society by caring for some of the most vulnerable in our country. The Alzheimer's Association and AIM look forward to working with the Committee to shape specific proposals to better train and support the direct care workforce in the future. In the meantime, we encourage the Committee to consider the following principles and facts regarding dementia care.

The [Alzheimer's Association's Dementia Care Practice Recommendations](#) include the following recommendations specific to workforce: (1) staffing levels should be adequate to allow for proper care at all times — day and night; (2) staff should be sufficiently trained in all aspects of care, including dementia care; (3) staff should be adequately compensated for their valuable work; (4) staff should work in a supportive atmosphere that appreciates their contributions to overall quality care because improved working environments will result in reduced turnover in all care settings; (5) staff should have the opportunity for career growth; and (6) staff should work with families in both residential care settings and home health agencies. Additionally, we know that consistent assignment is an important component of quality care for staff working with residents with dementia.

While much of the training for long-term care staff is regulated at the state level, we encourage the Committee to consider proposals that support states in implementing and improving dementia training for direct care workers, as well as their oversight of these activities. Training policies should be competency-based, should target providers in a broad range of settings and not limited to dementia-specific programs or settings, and should enable staff to (1) provide person-centered dementia care based on thorough knowledge of the care recipient and their needs; (2) advance optimal functioning and high quality of life; and (3) incorporate problem-solving approaches into care practices.

The Alzheimer's Association and AIM also believe that direct service staff (i.e., an employee whose work involves extensive contact with participants or residents), administrative staff (i.e., administrative and managerial staff), and other staff who have incidental contact with residents or program participants on a recurring basis (i.e., housekeeping, maintenance, or others) should all receive dementia training. More about specific training topic areas can be found in our Dementia Care Practice Recommendations.

We also urge the Committee to support states in the following efforts: (1) any training curriculum should be delivered by knowledgeable staff that have hands-on experience and demonstrated competency in providing dementia care; (2) continuing education should be offered and encouraged; and (3) training should be portable, meaning that these workers should have the opportunity to transfer their skills or education from one setting to another.

### **Quality Palliative and Hospice Care Workforce**

There is also a need to expand the number of quality palliative and hospice care workers. We urge the Committee to consider the bipartisan Palliative Care and Hospice Education and Training Act (PCHETA), which would ensure a high-quality palliative care and hospice workforce. Palliative

and hospice care can improve both the quality of care and quality of life for those with advanced dementia. Nursing home residents with dementia who receive palliative care at the end of life, compared with those who do not receive such care, are up to 15 times less likely to die in a hospital, nearly 2.5 times less likely to have a hospitalization in the last 30 days of life, and up to 4.6 times less likely to have an emergency room visit in the last week of life. Individuals with advanced dementia who are enrolled in hospice have a lower rate of dying in the hospital, a lower rate of hospitalization in the last 30 days of life, and better symptom management. However, the availability and quality of palliative and hospice care is a concern. In fact, less than half of surveyed nursing homes report having some sort of palliative care program. PCHETA would help ensure an adequate, well-trained palliative care workforce through workforce training, education and awareness, and enhanced research.

### **Home and Community-Based Services Workforce**

Expanded access to home- and community-based services (HCBS) is also 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. We urge the Committee to invest in strengthening the HCBS workforce through increased wages, benefits, and support. This is especially important as the majority of home care workers are disproportionately women of color.

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

Finally, we ask that you support an expansion of 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 all patients, including people living with Alzheimer's. Project ECHO is especially crucial during the COVID-19 pandemic, where the models are playing an important role in how health providers, public health officials, and scientists in real-time share best practices and information. For example, the Agency for Healthcare Research and Quality 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. Investing in Project ECHO models is an innovative way to improve the capacity of a quality healthcare workforce to meet the needs of a growing aging population, including primary care physicians, specialists, and long-term care workers.

## **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. We look forward to working with the Committee and other members of Congress in a bipartisan way to advance policies that will ensure a well-trained, adequate healthcare workforce.