



The Honorable Bernie Sanders
Chairman
United States Health, Education,
Labor and Pensions Committee
428 Dirksen Senate Office Building
Washington, D.C. 20515

The Honorable Bill Cassidy, M.D.
Ranking Member
United States Health, Education,
Labor and Pensions Committee
428 Dirksen Senate Office Building
Washington, D.C. 20515

March 20, 2023

RE: Information from Stakeholders on Health Care Workforce Shortages – Alzheimer’s Association and Alzheimer’s Impact Movement

Dear Chairman Sanders and Ranking Member Cassidy:

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 leadership on issues and legislation important to Americans with Alzheimer’s and other dementias, and their caregivers. We appreciate the opportunity to submit comments in response to your call to action on potential solutions to the health care workforce shortage, which will ensure aging Americans living with Alzheimer’s disease continue to receive access to well-trained and adequate care and support services.

Background

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 affiliate, working in a 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 the development of approaches to reduce the risk of developing dementia.

An estimated 6.7 million Americans age 65 and older are living with Alzheimer’s dementia in 2023. Total payments for all individuals with Alzheimer’s or other dementias are estimated at \$345 billion (not including unpaid caregiving) in 2023. Medicare and Medicaid are expected to cover \$222 billion or 64 percent of the total health care and long-term care payments for people with Alzheimer’s or other dementias. Total payments for health care, long-term care, and hospice care for people with Alzheimer’s and other dementias are projected to increase to

nearly \$1 trillion in 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

As the prevalence of Alzheimer's disease and other dementias increases, so does the need for members of the paid workforce who are involved in diagnosing, treating, and caring for those living with these diseases. The Alzheimer's Association's [2023 Alzheimer's Disease Facts and Figures](#) found that nearly 1.2 million additional direct care workers will be needed between 2020 and 2030 – more new workers than in any other single occupation in the United States. The shortage of geriatricians and other relevant specialists has been attributed to a combination of factors, including growth in demand due to population aging; substantively lower pay for geriatricians and neurologists compared with many other specialist physicians; an inadequate number of clinician educators with relevant specialties on the faculties of health professional schools; limited availability of incentives to choose these specialties, such as loan forgiveness programs; and the insufficient respect and recognition accorded to geriatricians and related specialists.

In response, we encourage the Committee to consider the following recommendations to expand and better support the health care workforce providing care for individuals living with Alzheimer's and other dementia.

Expanding Capacity for Health Outcomes (Project ECHO)

First, we ask that your developing legislation includes an expansion of the use of technology-enabled collaborative learning and capacity-building models, often referred to as Project ECHO. These education models 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. One successful training model is the Alzheimer's and Dementia Care ECHO® Program, which pairs primary care providers (PCPs) with multidisciplinary specialist teams through telementoring to develop their knowledge and confidence in dementia care. According to an evaluation of the program, which was launched in 2018 by the Alzheimer's Association, 94 percent of surveyed participants reported making changes in their delivery of dementia care due to the program and 87 percent reported higher job satisfaction. Project ECHO dementia models are helping primary care physicians in real-time understand how to use validated assessment tools appropriate for early and accurate diagnoses, educate families about the diagnosis and home management strategies, and help caregivers understand the behavioral changes associated with Alzheimer's.

Direct Care Workforce

The largest segment of the workforce that supports people living with dementia is the direct care workforce. People living with Alzheimer's and other dementia make up a significant portion of all long-term care residents, comprising 48 percent of residents in nursing homes and 34 percent of all residents in assisted living communities and other residential care facilities. As the

prevalence of Alzheimer's disease increases, so does the need for members of the paid dementia care workforce. From 2016 to 2026, the demand for direct care workers is projected to grow by more than 40 percent, while their availability is expected to decline. Twelve states will need to increase the number of practicing geriatricians at least five-fold to care for those projected to have Alzheimer's dementia in 2050. As noted above, an estimated 1.2 million additional direct care workers will be needed between 2020 and 2030 — more new workers than in any other single occupation in the United States.

Looking ahead, health care systems must continue to expand the range of medical professionals who are better trained to notice symptoms of Alzheimer's disease and other dementia, conduct structured cognitive screenings, refer individuals to other health care professionals for dementia assessment and/or diagnosis, communicate a care plan to patients and their families, and coordinate services with families, caregivers, and community resources. Nurse practitioners, physician assistants, and other care providers can play a greater role in dementia care delivery, particularly for rural and underserved communities. With training, support, and recognition, direct care workers can also provide more tailored care for people living with dementia. For example, they can implement non-pharmacological interventions to mitigate distress; observe and report changes to clinical team members; and educate and support family members.

The [Alzheimer's Association's Dementia Care Practice Recommendations](#) include the following recommendations specific to the health care 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.

We are grateful for the Committee's support of the Geriatrics Workforce Enhancement Program (GWEP), funded by the Health Resources and Services Administration, which comprises a network of 48 GWEPs across most U.S. states and two territories. As you know, the goals of this program are to educate and train the health care workforce to care for older adults in integrated geriatrics and primary care models, to partner with community-based organizations to address gaps in health care for older adults, to promote age-friendly health systems and dementia-friendly communities, and to address social determinants of health. In particular, the GWEPs are required to provide training to primary care and other health care providers on the 4Ms (What Matters, Medication, Mentation, and Mobility). Central to this framework with regard to "mentation" is screening for cognitive impairment annually and at changes in status, with referral to appropriate intervention as needed. We urge the Committee to prioritize the

reauthorization of GWEP to ensure there is a sufficient amount of caretakers who understand the specialized needs of the aging population.

In an effort to expand access to direct care and support, the Alzheimer's Association established the National Alzheimer's Call Center, which provides 24-hour, 7-day a week, year-round telephone support, crisis counseling, care consultation, and information and referral services in over 200 languages for persons with Alzheimer's disease, their family members, and informal caregivers. Trained professional staff and master's level mental health professionals (social workers and counselors) are available at all times. The Fiscal Year (FY) 2023 Consolidated Appropriations Act (P.L. 117-328) allocated \$2 million for the Alzheimer's Call Center, and we look forward to working with the Committee to continue funding this vital resource to individuals living with the disease as well as their caregivers during the FY 2024 appropriations process and the reauthorization of the Older Americans Act (P.L. 116-131).

Develop Payment Models to Support the Dementia Care Workforce

Next, we ask that you consider implementing alternative payment models to scale up the delivery of collaborative, comprehensive, and innovative care for aging Americans with dementia. In the current fee-for-service payment model, there is no incentive for a clinician to coordinate the delivery of care and services. It also rewards providers for billing for many different services, but not for providing quality health outcomes for their patients. However, there are different kinds of payment systems that *do* address these issues by paying for the value of the care, including better outcomes for beneficiaries.

As you know, the Center for Medicare and Medicaid Innovation (CMMI) is tasked with creating and testing innovative models of care delivery and payment to improve outcomes and reduce costs. It has funded dementia care management models in the past, and those models demonstrated that comprehensive, coordinated dementia care can reduce hospitalizations and emergency department visits and delay nursing home placement, thus improving outcomes and reducing total costs.

Despite their success, however, these dementia care management programs will not spread on their own under the current Medicare system due to the significant upfront financial investment that physician practices must make to launch them. Furthermore, Medicare does not provide reimbursement for many of the patient and caregiver services that are key to these programs' success, like caregiver support and community-based service referrals. We need a system that pays for more of the services persons living with dementia and their families need, and one that pays clinicians to deliver high-value — not high-volume — care.

Establishing a dementia care management (DCM) alternative payment model would be a collaborative and interdisciplinary alternative payment model supported by innovative dementia-specific approaches to payment methodology, patient assessment and eligibility criteria, and other key design parameters. By testing the effectiveness of current comprehensive

care management services for persons with dementia, a DCM would ensure high standards of care, pay providers a monthly amount based on the complexity and quality of patient care, provide support to caregivers, and require outreach to underrepresented populations. Further, enhanced coordination can advance more significant outcomes for providers, such as small practices and solo practitioners caring for patients with dementia. An analysis conducted by consulting firm Healthspieren found that better care through dementia care management would save the federal government nearly \$21 billion over 10 years while improving the quality of life for both individuals with dementia and their families.

In an effort to remedy this fragmentation of care, the Alzheimer's Association has supported the reintroduction of the bipartisan *Comprehensive Care for Alzheimer's Act* (S. 626), which would ask CMMI to implement a dementia care management model to test the effectiveness of comprehensive care management services. While this bill is not in the HELP Committee's jurisdiction, we encourage you to draw from this legislation and prioritize coordination of care when developing similar policies related to the health care workforce. Dementia Care Management models are designed to reach as many Medicare beneficiaries as possible, especially individuals from diverse communities and rural and medically underserved areas. This payment model is particularly useful in the dementia care workforce, as a change in payment structure to value-based payment is necessary to enable dementia care management to allow these programs to be financially feasible for health care providers and practices; especially smaller practices, rural practices, and inner-city community health centers.

Quality Palliative and Hospice Care Workforce

There is also a need to expand the number of quality palliative and hospice care workers. We ask that the Committee supports the bipartisan Palliative Care and Hospice Education and Training Act (PCHETA) once it is reintroduced, 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 are concerns. In fact, less than half of surveyed nursing homes report having some sort of palliative care program. The Palliative Care and Hospice Education and Training Act 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 for aging populations. 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 the 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. We remain supportive and enthusiastic about the work the Committee did last Congress around HCBS and we urge the Committee to use this developing legislation to continue investing 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.

Conclusion

The Alzheimer's Association and AIM greatly 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 in a bipartisan matter as you continue to develop legislation impacting the health care workforce and hope you will consider us a resource throughout the process, especially while the population of individuals living with dementia continues to grow.