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

United States Senate Special Committee on Aging
Hearing on "Assisted Living Facilities: Understanding Long-Term Care Options for Older Adults"

January 25, 2024

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging hearing on **"Assisted Living Facilities: Understanding Long-Term Care Options for Older Adults."** The Association and AIM thank the Committee for its continued leadership on issues important to the millions of individuals living with Alzheimer's and other dementia and their caregivers. This statement highlights the importance of policies that will help ensure a quality direct care workforce that can meet the unique needs of our nation's growing number of Americans living with Alzheimer's and other dementia.

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, which are projected to increase to more than $1.1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only growing more urgent.

Assisted living is one of the fastest-growing options for residential housing for older Americans. There are approximately 30,600 assisted living communities with nearly 1.2 million licensed beds in the United States today. Assisted living bridges the gap between living independently and living in a nursing home and more assisted living providers are offering services designed specifically for people with dementia.

Use and Costs of Long-Term Care for Individuals with Alzheimer's and Dementia

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. Twenty-four percent of Medicare beneficiaries with Alzheimer's or other dementias reside in a nursing home, compared with one percent of Medicare beneficiaries without these conditions. Approximately 75 percent of individuals with Alzheimer's disease diagnosed at age 70 will reside in a nursing home by age 80, compared with only four percent of the general population surviving to age 80. Given our constituents' intensive use of these services, the quality of this care is of the utmost importance. As a result, we encourage the Committee to consider the following recommendations to improve long-term care and support for the growing number of Americans affected by Alzheimer's and other dementia.

Best Practices in Dementia Care

Given our constituents' intensive use of these services, the quality of this care is of the utmost importance. To this end, the Alzheimer's Association developed the *Alzheimer's Association's Dementia Care Practice Recommendations*. Grounded in the fundamentals of person-centered care and published in a special supplement of *The Gerontologist,* the Dementia Care Practice Recommendations outline recommendations for quality care practices based on a comprehensive review of current evidence, best practice, and expert opinion. The Dementia Care Practice Recommendations were developed to better define quality care across all settings, including assisted living, and throughout the disease course. They are intended for professional care providers who work with individuals living with dementia and their families in long-term and community-based care settings.

Assisted living communities should ensure that the care and services provided have a **Person Centered Focus** which includes: (1) **Knowing the person living with dementia**. The individual living with dementia is more than a diagnosis. It is important to know the unique and complete person including his/her values, beliefs, interests, abilities, likes and dislikes — both past and present. This information should inform every interaction and belief; (2) **Recognize and accept the person's reality.** It is important to see the world from the perspective of the individual living with dementia. Doing so recognizes behavior as a form of communication, thereby promoting effective and empathetic communication that validates feeling and connects with the individual and his/her reality; (3) **Identify and support ongoing opportunities for meaningful engagement.** Every experience and interaction can be seen as an opportunity for engagement. Engagement should be meaningful to, and purposeful for, the individual living with dementia. It should support interests and preferences, allow for choice and success, and recognize that even when the dementia is most severe, the person can experience joy, and comfort, and meaning in life; (4) **Create and maintain a supportive community for individuals, families and staff.** A supportive community allows for comfort and creates opportunities for success. It is a community that values each person and respects individual differences, celebrates

accomplishments and occasions, and provides access to and opportunities for autonomy, engagement, and shared experiences; (5) **Evaluate care practices regularly and make appropriate changes.** It is important to regularly evaluate practices and models, share findings, and make changes to interactions, programs, and practices as needed. A culture of continuous quality improvement is a continuing theme throughout all of the recommendations.

Detection and diagnosis is one of two new areas of focus in the Dementia Care Practice Recommendations. Assisted living communities should: (1) make information about brain health and cognitive aging readily available to older adults and their families; (2) all non-physician care staff should be trained to know the signs and symptoms of cognitive impairment, that signs and symptoms do not constitute a diagnosis of dementia, and that a diagnostic evaluation is essential for diagnosis of dementia; (3) non-physician care staff should listen for concerns about cognition, observe for signs and symptoms of cognitive impairment, and note changes that occurs abruptly or slowly over time; (4) develop and maintain procedures for detection of cognition and referral for diagnostic evaluation; (5) use a brief mental status to detect cognitive impairment only if such testing is with the scope of practice of the non-physician care staff, the non-physician care staff has been trained to use the test, required consent procedures are know and used and there is an established procedure for offering a referral for individuals who score below a preset score on the test to a physician for a diagnostic evaluation; (6) encourage older adults whose physician has recommended a diagnostic evaluation to follow through on the communication; (7) support a better understanding of a dementia diagnosis.

Assessment and care planning is crucial to provide quality dementia care. Assisted living communities should: (1) perform regular, comprehensive person-centered assessments and timely interim assessments; (2) use assessment as on opportunity for information gathering, relationship building, education, and support; (3) approach assessment and care planning with a collaborative team approach; (4) use documentation and communication systems to facilitate the delivery of person-centered information between all care providers; (5) advance care planning is another continuing theme throughout the Recommendations. An early and ongoing discussion of what matters, including values, quality of life and goals of care, are essential for person-centered care. Encourage advance planning to optimize physical, psychosocial, and fiscal well-being and to increase awareness of all care options, including palliative and hospice care.

Medical management is the second new topic area of the Recommendations. Assisted living communities must ensure that: (1) non-physician staff adopt a holistic person-centered approach to care and embrace a positive approach to the support for persons living with dementia and their caregivers that acknowledges the importance of individuals' ongoing medical care to their well-being and quality of life; (2) staff understand the role of medical providers in the care of persons living with dementia and the contributions they make towards a shared vision of care; (3) staff are educated on common comorbidities of aging and dementia and encourage persons living with dementia and their families to talk with the person's physician about how to manage comorbidities in a residential setting; (4) nonpharmacologic interventions

are the first line of treatment in managing behavioral and psychological symptoms of dementia; (5) although nonpharmacological interventions are preferred, there are times when pharmacological treatment may be warranted for behavioral and psychological symptoms; (6) there is an understanding of the general principles for starting and more importantly, ending pharmacological treatments and there must be regular medication reviews to consider the discontinuation of medications when appropriate.

Information, education and support is crucial for persons living with dementia and their care partners. Assisted living communities should: (1) provide education and support early in the disease to prepare for the future; (2) encourage care partners to work together and plan together; (3) build culturally sensitive programs that are easily adaptable to special populations; (4) ensure education, information, and support programs are accessible during times of transition; (5) use technology to reach more families in need of education, information, and support.

A large majority of residents in assisted living need assistance with **Activities of Daily Living (ADLs)**. Assisted living communities should: (1) acknowledge support of ADL function must recognize the activity, the individual's functional ability to perform the activity, and the extent of cognitive impairment; (2) follow person-centered practices when providing support for all ADL needs; (3) when providing support for dressing, attend to dignity, respect and choice; and the dressing environment; (4) when providing support for toileting, attend to dignity and respect the toileting process, the toileting environment, and health and biological considerations; (5) when providing support for eating, attend to dignity, respect and choice the dining environment; health and biological considerations; adaptations and functioning; and food, beverage, and appetite.

Up to 97 percent of persons living with dementia experience at least one **Dementia-Related Behavior**, the most common being apathy, depression, irritability, agitation, and anxiety. Assisted living communities should: (1) identify characteristics of the social and physical environment that trigger or exacerbate behavioral and psychological symptoms for the person living with dementia; (2) implement non-pharmacological practices that are person-centered, evidence-based, and feasible in the care setting; (3) recognize the investment required to implement non-pharmacological practices, including staff training and equipment costs; (4) adhere to protocols of administration to ensure that practices are used when and as needed, and sustained in ongoing care; (5) develop systems for evaluating effectiveness of practices and make changes as needed.

An adequate and well-trained **Workforce** is fundamental to providing quality dementia care. Assisted living communities should: (1) provide a thorough orientation program for new staff, as well as ongoing training; (2) develop systems for collecting and disseminating person-centered information; (3) encourage communication, teamwork, and interdepartmental/interdisciplinary collaboration; (4) establish an involved, care and supportive leadership team; (5) promote and encourage resident, staff, and family relationships; (5) evaluate systems and progress routinely for continuous improvement.

To maintain a strong dementia care workforce assisted living communities should: (1) have staffing levels adequate to allow for proper care at all times — day and night; (2) ensure that all staff 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) ensure that staff have the opportunity for career growth. Additionally, we know that consistent assignment is an important component of quality care for staff working with residents with dementia.

A **Supportive and Therapeutic Environment** contributes significantly to the quality of life for persons with dementia. Assisted living communities should: (1) create a sense of community within the care environment; (2) enhance comfort and dignity for everyone; (3) support courtesy, concern, and safety; (4) provide opportunities for choice for all persons; (5) offer opportunities for meaningful engagement to members of the community.

Persons with dementia often have **Transitions** between assisted living and other settings including emergency rooms, hospitals, and nursing homes. Assisted living communities should: (1) prepare and educate persons living with dementia and their care partners about common transitions in care: (2) ensure complete and timely communication of information between, across and within settings; (3) evaluate the preferences and goals of the person with dementia along the continuum of transitions of care; (4) create strong interprofessional collaborative team environments to assist persons living with dementia and their care partners as they make transitions; (5) initiate/use evidence-based models to avoid, delay, or plan transitions of care.

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 state health departments in implementing and improving dementia training for direct care workers and 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 a 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.

We also urge the Committee to support state dementia efforts in the following ways: (1) any training curriculum should be delivered by knowledgeable staff that has 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.

Acuity-Based Staffing

Fifty-eight percent of assisted living communities offer programs for residents with Alzheimer's or other dementias, and 19 percent have a dementia care unit. Staffing requirements in long-term care settings providing dementia care vary by the setting and state. Residential care, including assisted living communities, is licensed by the respective state agencies, though most states do not specify minimum staffing levels or ratios in dementia care. Appropriate staffing ratio practices affect the quality of life for those in assisted living communities, especially those living with dementia. However, there is limited research identifying an optimal ratio of staffing.

In residential long-term care settings, staffing is a key driver of quality care. A review of scholarly literature on this subject verifies that there is a clear association between higher levels of licensed staff and higher quality of care. A resident's individual outcomes (including the presence of weight loss, bed sores, and general functional ability), are regularly linked to staffing and there is an association between higher turnover rates and lower quality of care.

Beyond meeting any mandatory staffing numbers required in organizations serving persons with dementia, there is a growing awareness of the need to deploy staff in a manner that aligns with resident routines and needs. A simple staffing ratio, while clear, may not be sufficient to consistently deliver high-quality care. The makeup of the resident population including, for example, the number of people with dementia, should impact the numbers of nursing staff present at any given time. Encouraging the implementation of acuity-based staffing models could improve the quality of care individuals receive in assisted living communities. Acuity-based staffing refers to "the allocation of clinical expertise and caregiver resources necessary to ensure a resident's quality of care/life, based on their medical complexity, ADL dependency, and behavior challenges, as defined by a formal assessment process."

For long-term care communities, developing the appropriate acuity-based nurse staffing levels can be challenging but existing research has provided guidance to inform facilities and policymakers. According to Harrington et. al. (2020), there are five steps to determine sufficient nurse staffing levels: (1) determine the collective resident acuity and care needs; (2) determine the facility's actual per resident per day staffing levels; (3) determine appropriate nurse staffing levels based on resident acuity; (4) identify evidence regarding the adequacy of staffing; (5) analyze the adequacy of facility staffing.

Expanding the Health Care Workforce Serving Older Adults

As highlighted above, while the prevalence of Alzheimer's disease increases, so does the need for well-trained members of the paid dementia care workforce. Shortages in direct care workers in long-term care settings will place an even bigger burden on family and friends who provide unpaid care — already an effort equivalent to nearly $257 billion annually. 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. The United States will have to nearly triple the number of geriatricians to effectively care for the number of people projected to have Alzheimer's in 2050, while efforts to increase recruitment and retention remain slow. In 48 U.S. states, double-digit

percentage increases in home health and personal care aides will be needed by 2028 to meet demand. 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.

Although more direct care workers will be needed in the years ahead, the long-term care field is already struggling to fill existing direct care positions. Turnover rates are high in this workforce — estimated at 64 percent annually for direct care workers providing home care and 99 percent for nursing assistants in nursing homes — and recruitment and retention are long-standing challenges. In turn, instability in the workforce and understaffing across care settings can lead to stress, injury, and burnout among direct care workers while also compromising care access and quality.

State-Level Actions to Improve Quality Dementia Care

The Committee may find the following state-based efforts instructive, and we would be pleased to provide additional examples at your request.

PENNSYLVANIA
In 2022, skilled nursing facility regulations were updated in Pennsylvania (Regulation No. 10-224 #3343) and require dementia training as part of all staff orientation.

In addition to looking to the states for ways to ensure safe, quality, person-centered care in assisted living facilities, Congress should consider the steps it can take at the federal level, including expanding the necessary workforce and improving dementia training standards and access.

GEORGIA
In Georgia, where there are currently over 150,000 individuals living with Alzheimer's, House Bill 987 (Act 403 of 2020) was enacted, establishing memory care licensure and dementia training for all direct care workers and all other LTC staff in memory care centers. The legislation requires that all Assisted Living Facilities and Personal Care Homes that offer memory care receive a certificate to operate from the Department of Community Health, and it requires the Department of Community Health to establish additional requirements to better serve people with dementia in memory care centers in the areas of (1) admissions, assessment, and care planning; (2) physical settings to accommodate and protect residents; and (3) protocols to prevent elopement.

Further, the legislation requires memory care centers to have at least one dementia-trained direct care staffer for every 12 residents during the daytime and one to 15 overnight (based on a monthly average); that all staff receive four hours of dementia training within their first 30 days of employment including (1) basic education on the process and management of Alzheimer's and other dementias; (2) reducing challenging dementia behaviors; (3) identifying and reducing

safety risks to residents with dementia; and (4) successful communication techniques with individuals with dementia. The legislation also required direct care staff in the memory center to receive at least 16 hours of specialized dementia training within their first 30 days of employment and eight hours of dementia training each year thereafter. The dementia training for direct care staff must incorporate (1) the nature of Alzheimer's and other dementias; (2) the center's philosophy related to the care of residents with dementia; (3) policies and procedures for dementia care; (4) dementia-related behaviors and positive interventions to reduce them; (5) maintaining the safety of the resident; and (6) the role of the family in caring for residents with Alzheimer's and other dementias.

INDIANA

Introduced in 2021, Indiana Senate Bill 169 (Public Law 48 of 2021) requires assisted living facilities that provide memory care services to disclose their dementia-specific care, staffing levels, and transfer/discharge policies. Introduced in 2022, Senate Bill 0353 (Public Law 44 of 2022) establishes dementia training standards for home health aides caring for people with dementia, requiring three hours of annual continuing education on dementia and six hours of initial dementia training for new hires.

Conclusion

The Alzheimer's Association and AIM appreciate the Committee's steadfast support and commitment to advancing issues important to the millions of individuals living with Alzheimer's and other dementia, as well as their caregivers. We look forward to working with the Committee and other members of Congress in a bipartisan way to advance policies that will ensure individuals living with Alzheimer's and other dementia have adequate access to high-quality assisted living and all long-term and community-based care services, especially as the population of Americans living with dementia continues to grow.