Center for Excellence
in Assisted Living
CEAL@UNC

Center for Excellence in Assisted Living
University of North Carolina at Chapel Hill

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 Center for Excellence in Assisted Living (CEAL) was established in 2003 in response to the U.S. Senate Special Committee on Aging's Assisted Living Workgroup Report, as a unique national collaborative of diverse organizations working together to promote excellence in assisted living. In 2023, CEAL joined with the University of North Carolina at Chapel Hill (UNC) to create a closer partnership with research and provide more capacity to advance the well-being of the people who live and work in assisted living through research, practice, and policy. Information about CEAL@UNC is available at its website.

CEAL@UNC appreciates the opportunity to submit this statement for the record to the Senate Special Committee on Aging regarding the hearing *Assisted Living Facilities: Understanding Long-Term Care Options for Older Adults*. The statement presents six interrelated topics that are central to understanding assisted living; each topic concludes with an issue that requires attention to improve assisted living going forward. The statement ends with potential actions for the future.

1. **Assisted living is referred to as a "*community*" rather than a "*facility*," reflecting its philosophy and variation.**
   The term "*community*" has been the preferred term for assisted living since the 1990's; in contrast to the word "*facility*," *community* intends to convey residential-style living, consumer autonomy, and person-centeredness.[1,2] In fact, assisted living is formally recognized as a home and community-based setting. Relatedly, the definition of assisted living is broad to allow for a range of person-centered options: *a congregate setting that includes "core services such as access to health-related, social and recreational services, as well as access to staff 24 hours daily. The core principles include resident-centered services and policies that promote each resident's quality of life, right to privacy, choice, dignity and independence as defined by that resident."*[3]
   - **Due to the range of assisted living communities and services, each community must provide clear and transparent information about their scope of services to allow consumers to make informed choices.**

2. **Assisted living is the largest provider of residential long-term care in the nation.**
   Most often, older adults and others who require supportive care initially receive that support from family and paid home care; when family and other home-based supports are no longer available or sufficient, they turn to residential care settings. Although there are more nursing home beds than there are beds/units/apartments in assisted living communities, half of older adults who require residential long-term care now receive it in assisted living (55% versus 45% in nursing homes); approximately 918,700 older adults reside in 31,400 assisted living communities across the nation.[4] However, the communities are disproportionately distributed; they are more often located in counties with a higher percentage of individuals who are non-Hispanic white (89% of residents are non-Hispanic white), and have a higher socioeconomic status and more education.[4,5]
   - **Expanding equitable access to assisted living services should be prioritized.**

3. **Assisted living is primarily private-pay, providing access to those who can afford it.**
   Assisted living evolved as a less expensive alternative to nursing home care for people who did not need intensive nursing services and could pay privately; it still largely relies on individuals' personal savings, retirement accounts, social security, pensions, and (if available) family members' incomes. The annual median cost for assisted living (in 2021) was $54,000,[6] which is out of reach for approximately 40% of middle-income older adults even after selling their home (but less expensive than nursing home care or around-the-clock home care).[7] Medicaid is available on a limited waiver basis to cover assisted living services (but not housing costs) in almost all states, but is available for roughly only one in five assisted living residents.[8]
   - **Steps must be taken to strengthen access to assisted living for the "forgotten middle" market of older adults.**

4. **<u>Assisted living residents have significant care needs, and many have Alzheimer's disease or related dementia.</u>**
   Health and supportive care options for older adults have been evolving over the last decades, changing the profile of assisted living residents. Shorter hospital stays have resulted in increased use of nursing homes for post-acute care following hospitalization, and individuals who do not require ongoing nursing care are now the residents of assisted living. Today, more than half of assisted living residents are 85 years of age or older, need help with mobility, and have medical, cognitive, and affective conditions.[9,10] Importantly, assisted living has become the largest residential care provider for persons with Alzheimer's disease or related dementia, including for persons with moderate or advanced dementia: 25% of communities are devoted to or have a unit devoted to memory care, compared to 14% of nursing homes.[11] Residents' care needs are multiple: based on Medicaid eligibility alone, 19% have needs that meet nursing home requirements,[8] and a notable portion receive end-of-life care in assisted living.[12]
   - **Service provision must consistently meet residents' needs for care.**

5. **<u>The quality of assisted living care depends on the quality and quantity of staff; providing care is labor-intensive.</u>**
   Staffing is the primary challenge for assisted living; wages are relatively low, and staff recruitment and retention are major concerns just as they are in nursing homes. Most residents' care needs are personal and supportive; in response, staff provide help with daily activities including bathing and locomotion, and attend to safety and social engagement.[4] Medical monitoring and medication management also are important, typically provided by non-nursing staff who have medication training. That said, nursing presence is more common in assisted living than in the past. Forty percent of communities have a registered nurse (RN); a similar percentage have a licensed practical/vocational nurse (LPN/LVN).[4] Depending on the community -- and consistent with the variability that is virtually definitional of assisted living -- available nursing services range from basic care such as monitoring vital signs to more complex care, such as providing intravenous medications.[13] Together with personal care assistants/aides, they provide roughly 4½ hours of care per day per resident, compared to 2¾ hours in nursing homes.[4] In addition to time, training is needed to help staff capably attend to residents' psychosocial care needs, especially for residents with dementia who commonly experience depression, irritability, agitation, and anxiety; all too often, these residents are treated with antipsychotic medications when staff do not have the time or are unaware of how to prevent or lessen their distress.[14,15]
   - **Sufficient numbers of well-trained staff are critically needed to strengthen assisted living care.**

6. **<u>Families play a vital role in assisted living.</u>**
   Families continue to provide care after a resident moves to assisted living, including monitoring health, well-being, and finances, and participating in end-of-life care.[16-18] The importance of families became especially evident during the COVID-19 pandemic when they became recognized as essential caregivers.[19-21] Families also are centrally involved in helping to choose an assisted living community for their relative, but often lack necessary information to make a knowledgeable decision about which communities would best meet their relative's needs and preferences.[22]
   - **Families require support to fulfil their role in assisted living to the best of their ability.**

Potential Actions

Numerous feasible solutions have been suggested that may improve care and outcomes in assisted living.[2] For example, related to the variability of assisted living, the need for consumer information, and the intent to promote person-centered care, solutions include (1) promoting consumer education using common definitions and providing relevant details (e.g., added charges, move-out policies); (2) endorsing standardized reporting (an effort that was begun by the federal government years ago, but not completed);[23] and (3) decoupling services from housing to promote choice. Access and equity could in part be addressed by (4) expanding Medicaid coverage; (5) diversifying housing options and modifying services; and (6) offering tax incentives and public subsidies to owners and operators who open the door to the forgotten middle market. The quality of care and outcomes could potentially be improved by (7) adopting regulations that encourage quality improvement (already being implemented in numerous states);[24] (8) promoting quality initiatives by implementing and evaluating promising programs, processes, and measures (for example, accreditation is currently being evaluated in the state of NC);[25] and (9) adhering to consensus recommendations for medical and mental health care.[10] Finally, staffing might become more sufficient if (10) guidance or standards for staff training, supervision, compensation, and other factors were explored; (11) supportive immigration policies were adopted;[11] (12) acuity-based staffing was established (which is actively being addressed in the state of OR);[26] and (13) funds were made available to support family involvement in care (for example, modeled off the U.S. Department of Veterans Affairs Program that provides stipends to family caregivers).[27] These examples are but a few of the potential solutions to address critical issues and improve care and outcomes in assisted living.

The Role of the Center for Excellence in Assisted Living@UNC

Since its inception 20 years ago, the mission of CEAL has been to advance the well-being of the people who live and work in assisted living through research, practice, and policy. Organizations involved in CEAL represent assisted living providers; nurses, physicians, and other clinicians; experts and advocates in Alzheimer's disease and dementia care; state agencies supporting long-term services and supports; leaders in eldercare transformation; workforce experts transforming quality direct care jobs; and numerous others. To note but a few of its efforts over the last years, CEAL has worked with researchers to develop quality measures for assisted living, examine the impact of potential minimum wage increases, and evaluate change in assisted living following the initial Assisted Living Workgroup Report provided to the U.S. Senate Special Committee on Aging in 2003.[28-32] Current efforts include consulting on the ongoing Centers for Disease Control and Prevention (CDC)-funded "Moving Needles" initiative to make routine immunization a standard of care in assisted living; leading the national Be Well in AL Coalition to promote adoption of recommended medical and mental health recommendations; compiling State Transitions Plans responsive to the Centers for Medicare & Medicaid Services (CMS) Home and Community-Based services regulations; and translating research for policy and practice, all available on the CEAL@UNC website.

CEAL@UNC welcomes the opportunity and stands poised to work with the Committee and other members of Congress in a bipartisan manner to advance excellence in assisted living.

References

[1] Wilson KB. Historical evolution of assisted living in the United States, 1979 to the present. Gerontologist 2007;47(S1):8-22.
[2] Zimmerman S, Carder P, Schwartz L, Silbersack J, Temkin-Greener H, Thomas KS, Ward K, Jenkens R, Jensen L, Johnson AC, Johnson J, Johnston T, Kaes L, Katz P, Klinger JH, Lieblich C, Mace B, O'Neil K, Pace DD, Scales K, Stone RI, Thomas S, Williams PJ, Williams KB. The imperative to reimagine assisted living. J Am Med Dir Assoc. 2022;23(2):225-234.
[3] Carder, P., Dys, S., Winfree, J. (2019). The Assisted Living Workgroup Report: A 15-Year Review. Washington, DC: Center for Excellence in Assisted Living [CEAL]. Available at theceal.org.
[4] Sengupta M, Lendon JP, Caffrey C, Melekin A, Singh P. Post-acute and long-term care providers and services users in the United States, 2017-2018. National Center for Health Statistics. Vital Health Stat 3(47). 2022. Available at https://stacks.cdc.gov/view/cdc/115346.
[5] Cornell PY, Zhang W, Smith L, Fashaw S, Thomas KS. Developments in the market for assisted living: residential care availability in 2017. J Am Med Dir Assoc. 2020;21(11):1718-1723.
[6] Genworth. Cost of Care Trends & Insights. Available at https://www.genworth.com/aging-and-you/finances/cost-of-care/cost-of-care-trends-and-insights.html/.
[7] Pearson CF, Murphy R, Gianattasio K, Loganathan, S. The Forgotten Middle: Housing & Care Options for Middle-Income Seniors in 2033. Available at chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.norc.org/content/dam/norc-org/documents/standard-projects-pdf/NORC%20Forgotten%20Middle%202022%20-%20Analysis%20and%20Findings.pdf.
[8] Caffrey C, Sengupta M, Melekin A. Residential care community resident characteristics: United States, 2018. NCHS Data Brief, no 404. Hyattsville, MD: National Center for Health Statistics. 2021.
[9] Zimmerman S, Sloane PD, Reed D. Dementia prevalence and care in assisted living. Health Aff (Millwood). 2014;33(4):658-666.
[10] Zimmerman S, Sloane PD, Wretman CJ, Cao K, Silbersack J, Carder P, Thomas KS, Allen J, Butrum K, Chicotel T, Giorgio P, Hernandez M, Kales H, Katz P, Klinger JH, Kunze M, Laxton C, McNealley V, Meeks S, O'Neil K, Pace D, Resnick B, Schwartz L, Seitz D, Smetanka M, Van Haitsma K. Recommendations for medical and mental health care in assisted living based on an expert Delphi consensus panel: a consensus statement. JAMA Netw Open. 2022;5(9):e2233872.
[11] Zimmerman S, Stone R, Carder P, Thomas KS. Does assisted living provide assistance and promote living? (In press). Health Aff (Millwood).
[12] Hanson LC, Eckert JK, Dobbs D, Williams CS, Caprio AJ, Sloane PD, Zimmerman S. Symptom experience of dying long-term care residents. J Am Geriatr Soc. 2008;56(1):91-98.
[13] Beeber AS, Zimmerman S, Reed D, Mitchell CM, Sloane PD, Harris-Wallace B, Perez R, Schumacher JG. Licensed nurse staffing and health service availability in residential care and assisted living. J Am Geriatr Soc. 2014;62(5):805-811.
[14] Dobbs D, Zimmerman S, Carder P, Beeber AS, Palmertree SJ. Staff reports of behavioral expressions of persons with dementia in 250 assisted living communities. Gerontologist. 2022;62(2):169-180.
[15] Scales K, Zimmerman S, Miller SJ. (2018). Evidence-based nonpharmacological practices to address behavioral and psychological symptoms of dementia. Gerontologist, 58(S1):88–102.
[16] Coe NB, Werner RM. Informal caregivers provide considerable front-line support in residential care facilities and nursing homes. Health Aff (Millwood). 2022;41(1):105-111.
[17] Port CL, Zimmerman S, Williams CS, Dobbs D, Preisser JS, Williams SW. Families filling the gap: comparing family involvement for assisted living and nursing home residents with dementia. Gerontologist. 2005;45(S1):87-95.
[18] Williams SW, Zimmerman S, Williams CS. Family caregiver involvement for long-term care residents at the end of life. J Gerontol B Psychol Sci Soc Sci. 2012;67(5):595-604.
[19] Zimmerman S, Sloane PD, Katz PR, Kunze M, O'Neil K, Resnick B. The need to include assisted living in responding to the COVID-19 pandemic. J Am Med Dir Assoc. 2020;21(5):572-575.
[20] Kemp CL. #MoreThanAVisitor: families as "essential" care partners during COVID-19. Gerontologist. 2021;61(2):145-151.
[21] Zimmerman S. Families are not informal -- they are an essential solution to the workforce crisis in long-term care. J Am Med Dir Assoc. 2022;23(7):1121-1122.
[22] Zimmerman S, Cohen L, Horsford C. Group proposes public reporting for assisted living. Provider. 2013;39(12):40-42.
[23] U.S. Department of Health & Human Services. Assisted Living Disclosure Collaborative. Available at https://archive.ahrq.gov/research/findings/factsheets/aging/aldc/index.html
[24] American Health Care Association/National Center for Assisted Living. State Regulatory Resources. Available at https://www.ahcancal.org/Assisted-Living/Policy/Pages/state-regulations.aspx.
[25] Senate Bill 105: 2021 Appropriations Act, Sec. 9E.6: Adult Care Home Accreditation Pilot Program. February22, 2022. Available at chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://dashboard.ncleg.gov/api/Services/BillSummary/2021/S105-SMSH-118(sl)-v-5.
[26] Oregon Department of Human Services. Acuity-Based Staffing. Available at www.oregon.gov/odhs/licensing/community-based-care/pages/acuity-based-staffing.aspx.
[27] Kuntz AA, Wanninger E, Lewis B. (2022). Caregiver support in a case of posttraumatic stress disorder and Lewy Body dementia. Federal Pract 2022; 39(5):226–231.
[28] Zimmerman S, Allen J, Cohen LW, Pinkowitz J, Reed D, Coffey WO, Reed P, Lepore M, Sloane PD; University of North Carolina-Center for Excellence in Assisted Living Collaborative. A measure of person-centered practices in assisted living: the PC-PAL. J Am Med Dir Assoc. 2015;16(2):132-137.
[29] Zimmerman S, Love K, Cohen LW, Pinkowitz J, Nyrop KA. Person-centeredness in home- and community-based services and supports: domains, attributes, and assisted living indicators. Clin Gerontol. 2014;37(5):429-445.
[30] Zimmerman S, Cohen LW, Washington T, Ward K, Giorgio P. Measures and Instruments for Quality Improvement in Assisted Living. Available at https://theceal.org/resources/measures-and-instruments-for-quality-improvement-in-assisted-living/
[31] Weiner JM, Elkins W, Lepore M. Impacts of Potential Minimum Wage Increases on Assisted Living and Continuing Care Retirement Communities. Available at chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://theceal.org/wp-content/uploads/2017/09/RTI-CEAL-Minimum-Wage-Report-2017-FINAL.pdf.
[32] Carder P., Dys S, Winfree J. 15 Year Review: The Assisted Living Workgroup Report. Available at chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://theceal.org/wp-content/uploads/2023/01/CEAL-Workgroup-Report-010920.pdf.