LeadingAge Testimony for the Record
U.S. Senate Special Committee on Aging Hearing:
“Assisted Living Facilities: Understanding Long-Term Care Options for Older Adults”
January 25, 2024

Chairman Casey, Ranking Member Braun, and distinguished members of the Senate Special Committee on Aging (the Committee), we appreciate the opportunity to submit written testimony from LeadingAge on your hearing titled, “Assisted Living Facilities: Understanding Long-Term Care Options for Older Adults”.

LeadingAge represents more than 5,000 nonprofit aging services providers, and other mission-minded aging services organizations. Alongside our members and 36 state partners, representing 41 states, we use applied research, advocacy, education, and community-building to make America a better place to grow old. Our membership encompasses the continuum of services for people as they age, including serving older adults with complex care needs in assisted living settings.

Most of LeadingAge’s members who provide assisted living services do so as one component of multi-service settings. Almost all are nonprofit organizations. In 2020, approximately 17.1% of the nation’s assisted living organizations were classified as nonprofit providers. Similar to other long-term care settings, that percentage is trending down.

The Committee’s focus today on critical issues in long-term services and supports, and assisted living specifically -- access, quality, staffing, and financing issues – are top concerns of LeadingAge and our members. Quality care in every care setting, including assisted living, is our top priority. In addition, we embrace state efforts to balance the need to protect the safety of residents while maximizing autonomy and providing the highest quality care. This is the goal of assisted living.

We Have No Tolerance for Bad Care

LeadingAge and our nonprofit, mission-driven members are committed to improving quality of care and quality of life for older adults. We make no apology or excuses for poor quality of care; bad performers must improve and there must be accountability for wrongdoing. Every assisted living community should be striving for excellence every day.

We support state systems that provide complete transparency about complaints, their resolution, and quality ratings so that consumers have all the knowledge they need before they move into a residential setting. We do not believe it would be effective to attempt imposing a federal regulation or reporting structure on a set of services that evolved to respond to state and local consumer interest in supportive care – but not nursing care – and a distaste for nursing homes. Multiple models can be successful.

In addition to being an unsuitable fit and the prohibitive costs of a misaligned regulatory overlay, a federal standards and enforcement system for a service that is primarily purchased privately by consumers using their own funds, however limited, will not improve quality. Rather, a federal regulatory system would dramatically halt innovation and drive the best providers out of the field, limiting consumer options just as our aging population needs more, not fewer good providers of care.
We would like to use this opportunity to make several key points:

- There is no federal definition of assisted living and minimal federal funding.
- Equity in access is a significant concern and lack of options severely limits the ability of older adults and their families to find the right care for their situations. The vast majority of assisted living spending is by consumers, out of pocket. Only 17.5% of spending is generated from public sources, primarily the state-federal Medicaid program. In addition to inadequate funding, structural barriers in Medicaid hinder access to Medicaid-funded assisted living care.
- Assisted living providers must, above all, provide high-quality, person-centered care and transparent reporting. Providers who consistently offer poor care should not be in business. States should take swift enforcement action to ensure these providers are not allowed to harm seniors.
- Federal investment in the caregiving workforce is needed immediately. This should include training resources, including a focus on dementia care, pipeline programs, and expedited immigration for those willing to move to the U.S. to work in long-term care. The impact of the Biden Administration’s nursing home staffing mandate, if implemented as proposed, will reverberate throughout the healthcare system; assisted living providers will compete with others to recruit and retain the limited number of available workers.
- As the population of the country continues to age, there will be fewer family caregivers and increasing older individuals seeking quality residential care they can trust. Families seeking assisted living services and their family members need resources to better understand the options and the costs.
- Assisted living – all long-term care – has costs attached to it. Most older people and their families cannot afford care today and, as time goes on, even more will not have the funds to pay for the help they need. Comprehensive long-term care financing is urgently needed.

We offer recommendations for the Committee’s consideration:

- Establish and fund a clearinghouse and technical assistance center to expand knowledge about the wide variety of state approaches to regulating assisted living, evaluate their impact on quality, including consumer satisfaction, and support adoption of the most effective models by states.
- Take steps immediately to expand domestic and international pipelines to increase the pool of committed, qualified people available to deliver care to residents.
- Establish and fund a national resource center for assisted living staff training, including training in dementia care.
- Provide more federal funding through the Department of Health and Human Services’ (HHS) Administration on Community Living to support the development of federal and state consumer materials to help people seeking care in assisted living settings that cover: the service offering; complaints reported, resident quality ratings, and the cost of care.
- Take steps to establish a national system to finance long-term care services to ensure that the 50% of people over age 65 who will need paid long-term care before they die have options and financing to cover their care.
The remaining sections of this testimony describe these key points and recommendations in more detail.

**States Define and Regulate Assisted Living**

Assisted living emerged from a community need for residential places where older people could live safely and relatively independently, with access to care and services if they need them. It had its roots in the belief that a non-medical, non-nursing home setting was missing – with the goal of providing options for people who needed some support they could not easily get in their home in the community, but less than the more intensive care provided by nursing homes.

Absent common agreement on the definition of assisted living, multiple models have continued to evolve based on what developers and providers have offered and states have regulated. The HHS/Centers for Disease Control and Prevention (CDC) National Center for Health Statistics (NCHS) spent years creating a very basic definition for the purpose of conducting what is now known as the residential living component of the National Post-Acute and Long-Term Care Survey (NPALS), the only federal source of national data on assisted living.

That definition includes “a care setting regulated by states to provide room and board to 4 or more residents, at least 2 meals a day, around the clock supervision, and help with personal care to a predominantly adult population.” Using those parameters, NCHS identified 28,900 communities across the U.S. in 2020, serving just under 1 million people. However, there is enormous variation across models that are offered and regulated, with extensive inconsistency in the balance of medical and social models.

While that diversity promotes innovation and consumer-responsive models, it also makes it challenging to agree on minimum components and regulatory requirements. Over the past three decades, as assisted living has become more widely offered across the country, there have been calls for federal regulations similar to the approach used in nursing homes.

With more than 50 different definitions and regulatory approaches and very little federal (or even public) funding, it is unclear how the federal government would define assisted living.

One particular concern is that attempts to impose federally mandated staffing ratios could force closures of many assisted living communities. The wide diversity of models in the cluster of communities under the rubric of assisted living means that there will never be one “right” staffing ratio.

A federal regulatory system aimed at the minority of “bad actors” will be ineffective and inefficient. Targeting punitive policy interventions to the lowest common denominator has not achieved its intended goal of quality improvement; there’s little reason to believe similar efforts in assisted living would be successful. Most LeadingAge members say that providers who routinely do not protect the safety of residents should not be offering assisted living (or any) services to older people.

Finally, the CMS-state nursing home survey enterprise – that must reach the country’s 15,000 nursing homes - is suffering terribly from both the same staffing challenges faced in long-term care settings, with long delays, and inadequate state-federal funding.

LeadingAge partners with the National Association for Regulatory Administration (NARA) and three other associations to create the Quality in Assisted Living Collaborative (QALC), to identify, define, and develop model guidance for assisted living. The Collaborative’s resources will be available to aid and educate providers, regulators, policymakers, and other stakeholders.
Recommendations:

- **Congress should establish and fund a clearinghouse and technical assistance center to expand knowledge about the wide variety of state approaches to regulating assisted living, evaluate their impact on quality, including consumer satisfaction, and support adoption of the most effective models by states.**

- **Members of the Committee might want to review the work of the Quality in Assisted Living Collaborative (the NARA collaborative work). Provider organizations are working together to identify a set of recommended guidelines for states to consider adopting. They are beginning with guidelines related to infection prevention and control.**

Consumers Do Not Consistently Have the Information They Need About Services Offered, Costs, Quality Reporting and Transparency

Individuals looking for an assisted living community for themselves or a loved one are already in a stressful position. They should have access to all the information they need, including the total cost of housing, care, and services. If there are going to be additional costs, consumers should know this up front. Recent articles in the media have highlighted stories of consumers caught unaware by unanticipated added costs.

The information available to consumers in some states includes complaints that have been made and how they have been resolved. To help consumers make good decisions, transparency about staffing, ownership and complaints is essential. LeadingAge supports efforts in a number of states to maintain online reporting of complaints and some consumer ratings of quality.

**Recommendation:**

- **Provide more federal funding through the HHS Administration on Community Living to support the development of federal and state consumer materials to help people seeking care to understand what they are being offered, complaints reported, resident quality ratings, and the cost of care before they move in.**

Staff are Paramount to Quality: The Workforce Shortage Limits Access to Good Care

Successful aging services organizations employ enough staff to meet their commitment to provide high quality care. Like the entire field of aging services and most other industries in the nation, assisted living providers face near-paralyzing shortages of staff, particularly frontline, direct service staff (e.g., personal care aides), dining, and activities. In organizations (and states) that require nurses, the nursing shortage is clearly felt across assisted living communities.

Members of LeadingAge report that as many as 20% of vacant positions go unfilled, with no applicants. Because they are mostly nonprofit, mission focused providers, they limit admissions if they do not have staff to serve people.

In an environment with unemployment rates consistently below 3%, aging services providers compete with retail, restaurant, and entertainment venues, where entry level employees can earn as much or more per hour for work that is typically less taxing and less complex.
It is gratifying that many workers in LeadingAge organizations argue that aging services jobs are more rewarding than other similarly paid positions. However, it is essential to understand that the skills, abilities, knowledge, and commitment required to work in assisted living settings should also be more highly valued. LeadingAge member communities report holding frequent conversations and town meetings with residents to connect monthly costs to staff wages.

An article in the January 21 Washington Post reported that teenage workforce participation has reached a 14 year high. Many LeadingAge provider members have joined with local high schools and community colleges to invite young workers, early in their careers to check into jobs available in long-term care. Many seasoned leaders in long-term care tell stories of starting in aging services in their teen years. These provider school partnerships require dedication, but they also require the formal attention of policymakers and funding. The Health Resources Services Administration’s training programs are limited in scope and reach. We need more as well as dedicated funding for the aging services workforce, including for assisted living staff.

Many aging services providers, again, like other industries, faced with an economy that typically has 1.5 jobs for every available job seeker, turn to other countries to recruit and hire staff. For a few select professional categories (including nurses), the U.S. immigration system offers some legal pathways to employment. However, these visa programs are difficult and expensive to navigate, require the coordination of at least three federal departments, and LeadingAge members report delays of anywhere from two to ten years.

There are no such opportunities for frontline workers in jobs that do not require at least a bachelor’s degree. Yet, one in four direct care workers in the U.S. were born in other countries. These individuals have mostly come to the United States as part of a family (“chain migration”). LeadingAge members report that they are some of the most dedicated staff members, and, in fact, the best recruiters, often bringing relatives and friends into the organization too.

The U.S. immigration system is broken at a time when we cannot fill jobs with native born workers. There are not enough people to fill the jobs, much less qualified, committed people. Policymakers frequently fall into the false assumption that issues with illegal border crossing and legal immigration are two separate issues. Expert observers note that to fix illegal border crossing issues we must fix the root cause, our outdated legal immigration system.

**Recommendations**

- **Take steps immediately to expand domestic and international pipelines so there are more committed, qualified people available to deliver care to residents.**
- **Modify current immigration authorities to expedite processing of applications for workers in aging and long-term care settings.**
- **Establish new immigration channels for frontline workers.**
- **Promote refugee resettlement program partnerships with aging services provider organizations.**

**Ongoing Evidence Based Training is Inconsistent**

Just as service definitions, staffing requirements, and regulations differ from state to state and across provider organizations, training and minimum qualifications vary as well. As they serve more and more people with increasingly higher levels of need, assisted living communities require more highly skilled professionals—with a range of skill sets, from clinical care to “soft skills” needed for delivery of
activities of daily living. The latter are developed over time and are more difficult to measure based on a universal standard.

As noted earlier in this testimony, individuals entering positions in assisted living must be well trained, using evidence-based methods, in a wide array of essential skills. They must receive continuous, ongoing in-service training to expand their skills and keep up with rapidly changing demands, needs, and knowledge.

Extensive training materials are available for frontline staff but many providers, especially smaller, single site organizations, are confused by the offerings. There are no tried and true ways to evaluate which work and in what settings. Which are evidence based? Marketers may stretch the underlying science to sell a training product. There is no neutral party to help providers select the best training.

In addition, training programs can be costly and out of reach for many smaller providers, particularly those who depend more heavily on Medicaid dollars and serve residents with lower incomes.

Further, onerous and outdated requirements for certified nurse aide programs make it exceedingly difficult to launch and sustain direct care training programs.

At the same time training enables staff members to increase their value to the organization – and their ability to provide even better care and services to residents – wages and job opportunities must keep pace or individuals will leave to seek better positions where they can keep growing.

Competitive wages are critical to recruiting and retaining direct care staff who work in long term care, including assisted living. Our Making Care Work Pay research, using publicly available data and standard economic simulation techniques, demonstrates that higher wages would bring myriad benefits to direct care workers, the direct care field, care recipients, and local communities—for a relatively modest cost.

Increased wages are one of several changes needed to recruit and retain a stable direct care workforce in long-term care, including assisted living.

**Recommendations**

- Establish and fund a national resource center for assisted living staff training, including training in dementia care.
- Review the LeadingAge LTSS Center @UMass Boston publication “Feeling Valued” Vision for Professionalizing the Direct Care Workforce, which offers strategies for reimagining the professional direct care workforce across long-term care settings.
- Create a national training curriculum and testing program for direct care workers.

Most Americans Cannot Access Care Because They Cannot Afford It

Assisted living is one of the few care settings in which government reimbursement through either Medicare or Medicaid is not the most common payer. Assisted living is almost exclusively out-of-pocket, private pay. Medicare does not cover long-term care, including assisted living services. Medicaid can cover the services offered in an assisted living but cannot pay for the room and board components of meals or shelter. But fewer than half of assisted living providers accept any Medicaid funds because the rates simply do not cover the cost of care.
It is not surprising that 90% of residents in assisted living identify as white, non-Hispanic, while the Census bureau reports that two-thirds of Americans identify with this racial group. Access to all long-term care depends on the ability to pay. The inequities in assisted living are especially stark.

By 2033 there will be more people in the United States over the age of 65 than under the age of 18. While lower income people are losing years of expected high quality life, wealthier Americans are gaining in life expectancy, further increasing disparities.

Half of Americans turning 65 will need some amount of paid long-term care before they die, typically 18 months to 2.5 years. The average cost of care in assisted living is $4,500 per month, or $54,000 annually.7 Few Americans plan for a healthy retirement let alone for the possibility or likelihood that they will need to also pay for long-term care.

When Medicare was created in 1965, most individuals did not live much past the age of 65. If they did and they required help, many more family members were available to provide that help, along with a place to live. Churches and other nonprofit community organizations filled in for those without caregivers.

Today, people are living much longer, they have fewer caregivers, and many more organizations exist to serve them. But few people can afford the care they need -- only the very wealthy, with sufficient out of pocket resources and those with incomes and resources low enough to qualify for Medicaid. This situation exacerbates equity concerns.

Aging services – long-term care – is an essential part of health care and, like the rest of health care, it has a price tag. Long-term care financing reform is essential – to ensure that all Americans are able to have choices about how and where they get the help that many of them will need in their later years. As a nation we committed in 1965 to not allowing older people to impoverish themselves and lose years of life because they cannot pay for the health care they need. It is long past time for bold policymakers to finish making good on the commitment.

Recommendation

- Take steps to establish a national system to finance long-term care services to ensure that the 50% of people over age 65 who will need paid long-term care before they die have options and financing to cover their care. The various public and public-private options have been identified and discussed for decades. Bold policymakers must step up and take action.

Medicaid Barriers Impede Equitable Access to Care

For the 17.5% of assisted living care that is covered by Medicaid, there are additional, unique challenges. In 48 states, assisted living is provided as a Medicaid service, typically under a waiver, but it is considered a home and community-based service.8 Unlike nursing home care, it does not cover room and board, which must come out of Social Security/SSI. Reimbursement for Medicaid funded assisted living makes it a challenging service to offer – this financial challenge combined with regulatory barrier contributes to the dearth of options available.

As a home and community-based service, assisted living services must be delivered in a manner that is person centered, optimizes community integration, and protects residents according to requirements outlined in the “HCBS Settings” or “Olmstead” rule. They include, for example, restrictions about locked doors and outings into the community. The requirements of the settings rule
have been open to interpretation by state agencies and, in many cases, make it nearly impossible to provide assisted living under Medicaid, leading to even more concerns about equity in access and quality -- some members have reported a chilling effect on their state’s willingness to offer Medicaid funded assisted living or expand the availability.

Recommendation

- Congress should authorize and appropriate funds to study policy barriers to states offering Medicaid assisted living including funding and the settings rule and other existing regulations. The report should offer policy options to expand the availability and viability of Medicaid funded assisted living.

CONCLUSION

Chairman Casey, Ranking Member Braun, and members of the Committee, LeadingAge appreciates this opportunity to provide written testimony for the January 25 hearing on assisted living and we stand ready to introduce you to our nonprofit, mission driven provider members across the country. If you would like to meet or discuss issues raised in this written testimony or any other long-term care or aging services related issues, please contact Ruth Katz, Senior Vice President for Policy and Advocacy (rkatz@leadingage.org).
1 Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics’ National Post-acute and Long-term Care Study (NPALS) Table 1, as accessed at https://www.cdc.gov/nchs/npals/webtables/overview.htm on January 23, 2024.
3 Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics’ National Post-acute and Long-term Care Study (NPALS) Table 1, as accessed at https://www.cdc.gov/nchs/npals/webtables/overview.htm on January 23, 2024.
4 Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics’ National Post-acute and Long-term Care Study (NPALS) Table 1, as accessed at https://www.cdc.gov/nchs/npals/webtables/overview.htm on January 23, 2024.