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COMMENTARY

Does Assisted Living Provide Assistance And Promote Living?

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ABSTRACT Assisted living has promised assistance and quality of living to older adults for more than eighty years. It is the largest residential provider of long-term care in the United States, serving more than 918,000 older adults as of 2018. As assisted living has evolved, the needs of residents have become more challenging; staffing shortages have worsened; regulations have become complex; the need for consumer support, education, and advocacy has grown; and financing and accessibility have become insufficient. Together, these factors have limited the extent to which today's assisted living adequately provides assistance and promotes living, with negative consequences for aging in place and well-being. This Commentary provides recommendations in four areas to help assisted living meet its promise: workforce; regulations and government; consumer needs and roles; and financing and accessibility. Policies that may be helpful include those that would increase staffing and boost wages and training; establish staffing standards with appropriate skill mix; promulgate state regulations that enable greater use of third-party services; encourage uniform data reporting; provide funds supporting family involvement; make community disclosure statements more accessible; and offer owners and operators incentives to facilitate access for consumers with fewer resources. Attention to these and other recommendations may help assisted living live up to its name.

As of 2018, almost 1.7 million people in the US required and received residential long-term care; more than half (918,700) resided in assisted living.[1] Many more could reside in assisted living if they had the resources to do so or if sufficient public funding were available. The question is, Should they live there? A recent paper authored by twenty-four national experts vehemently called for reimagining assisted living as a result of tensions related to models of assisted living, financing, regulation, the workforce, and rising resident acuity.[2]

At its core, assisted living provides at least two meals a day, around-the-clock supervision, and help with personal care but is not licensed as a nursing home; therefore, its capacity to address complex care needs is limited. However, chronic illness and functional impairment are common among residents. For example, as many as 70 percent have been found to have cognitive impairment, one-quarter displayed depressive symptoms, 11 percent had serious mental illness, and more than one-quarter had six or more chronic conditions; also, three-quarters needed assistance with bathing, and half had difficulty getting out of bed.[1,3–5] Although these numbers are not as high as in nursing homes, where almost twice as many nursing home residents were found to have depressive symptoms and virtually

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all required assistance with bathing,[1] assisted living residents' needs are substantial.

Attesting to the prevalence of psychosocial needs, assisted living has become the primary residential care setting for people with Alzheimer's disease and related dementias (ADRD): Between one-third and almost one-half of residents have been found to have ADRD.[1,4] Although the majority of residents with ADRD do not live in dedicated memory care units, assisted living has many more such units than do nursing homes: As of 2018, one-quarter of assisted living communities either exclusively served people with ADRD (6 percent) or had a unit, wing, or floor dedicated to people with ADRD (19 percent); in contrast, 14 percent of nursing homes provided exclusive or dedicated dementia care in 2018.[1]

In many ways, assisted living has been a natural experiment, exposing people to different types of settings over time. Dating back to board-and-care models of the 1940s that included room and board but did not promote or provide privacy, independence, or health-related services, assisted living has been evolving ever since. In the late 1980s and early 1990s, new models emerged that promoted autonomy in homelike settings. Oregon's model emphasized choice and the capacity to provide health-related services, while East Coast models focused on hospitality and supportive services.[6] Both models provided small apartment-style units and congregate dining, and they were staffed by personal care aides who received on-the-job training.

The evolution from early models to current options has not been planful or coordinated, and numerous types of assisted living now exist. Notably, although the term "assisted living" is commonly used, it is not a uniform concept; as of 2018, states used 182 license classifications that could be combined in 350 different ways to oversee assisted living,[7] creating widespread confusion. Further, the nursing home industry has raised concerns about regulation because nursing homes have lost revenue for lower-acuity private-pay assisted living residents who would otherwise reside in nursing homes.[8]

A key differentiator between nursing homes and assisted living has been that assisted living grounds itself in providing personalized supportive services (*assistance*) focusing on resident independence, dignity, privacy, and choice and minimizing the need to move (*living*).[9] Thus, this philosophy of assisted living is well aligned with the age-friendly intent to adapt services in response to residents' needs and preferences.[10] In reality, however, as the field has evolved and resident acuity has increased, assisted living has become both short on *assistance* and short on *living*: Necessary support is not always available, and aging in place and maximizing psychosocial well-being are not always feasible or practiced. Online appendix 1 illustrates the interplay between *assistance* and *living*, demonstrating that as assisted living residents' care needs increase, so too must assistance to enable residents to achieve the highest practicable quality of life.[11]

The current stage of the assisted living experiment demands questioning the extent to which these settings sufficiently merit the terms *assisted* and *living*. This Commentary identifies four issues that are implicated in the shortcomings of *assistance* and *living*: the limitations of the workforce; the complexity of regulation and the role of government; the need for consumer support, education, and advocacy; and the lack of sufficient financing and accessibility. All four issues have practice, policy, and research implications, which if sufficiently addressed might ultimately achieve the initial intent of assisted living. (In addition to sources cited in the article, appendix 3 includes a list of supplemental sources that may be of interest to readers.)[11]

Limitations Of The Workforce

THE ISSUES Given the rise in acuity, assisted living residents need a particularly competent, stable workforce to care for their medical and psychosocial needs—in essence, to ensure that they are *assisted* and to promote the quality of their *living*. Much like nursing homes, assisted living communities face a serious staffing shortage, with an only slightly better staff retention rate (66 percent in assisted living and 61 percent in nursing homes, according to a 2017 statewide study).[12] In June 2022, two-thirds of a national sample of assisted living administrators reported moderate or high staffing shortages, with 90 percent finding it difficult to hire new staff and almost 50 percent concerned that they would close if workforce challenges persisted.[13] Historically low wages, poor working conditions and benefits, and inadequate supervision contribute to high turnover and challenges with staff recruitment. To make matters worse, new federal nursing home staffing requirements, although beneficial for nursing home residents, could further limit the number of staff available to work in assisted living.[14]

In many ways, the workforce situation in assisted living looks even grimmer than in nursing homes. The majority of assisted living care is delivered by direct care workers who are unlicensed personal care or home care aides and, to a lesser extent, by certified nursing assistants. The most common direct care staffing ratio mod-

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el is flexible, as-needed staffing, defined without a number but instead as a "sufficient" number of staff adequately trained to meet residents' needs.[15] Perhaps for this reason, there have been class-action suits from consumers related to insufficient staffing in assisted living.[16] In part as a result of workforce shortages and low staffing, family caregivers have become an essential but unpaid part of the assisted living workforce.[17]

Furthermore, training requirements for direct care staff are minimal, with barely a third of states stipulating even a minimum number of training hours—and some requiring as little as one hour.[18] Staff often lack sufficient training in critical areas such as dementia care, care for people with complex needs, and infection control. Because of minimal direct care staff training and rising resident need, 71 percent of assisted living communities provided nursing services as of 2018.[1] However, nursing care is highly variable, with the amount and type of nursing ranging widely from basic services (such as monitoring vital signs) to gastrostomy and intravenous medications; in addition, many services are provided by outside staff,[19] indicating the importance of third-party services. Further, as of 2018, only 13 percent of communities employed a social worker[1] despite the extent of cognitive impairment, depression, and serious mental illness—and the assertion of assisted living to promote psychosocial well-being (*living*).

POLICY IMPLICATIONS Supportive immigration policies are one strategy to increase the workforce, as are increased wages for direct care workers.[20] Current proposed regulation by the Centers for Medicare and Medicaid Services would require that at least 80 percent of Medicaid payments for personal care, homemaker, and home health aide services be used for direct care wages.[21] However, even if implemented, the regulation would not likely have a significant impact because only 15 percent of assisted living revenue is derived from public sources.[22] An alternative option is that assisted living operators voluntarily realign their revenue, given that the majority of assisted living is private pay, and estimated profit margins of 20–40 percent are higher than those of most other health care providers.[23]

Promising initiatives to advance the competence of assisted living workers include the use by some states of American Rescue Plan Act funds to train and increase the size of the workforce.[24] Departments of Labor could also direct federal and state employment and training funds to the assisted living sector,[25,26] perhaps highlighting dementia care training because all states, through their regulation of assisted living, have at least one dementia care requirement

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(for example, conducting a preadmission assessment).[27] As another option, the Health Resources and Services Administration's Geriatric Workforce Enhancement Program could build a pipeline for assisted living employment and collaborate with professional schools, organizations, and universities to train and expand the workforce.[28]

In addition, there is need to define the types and roles of clinical staff and establish overall staffing ratios. An expert Delphi consensus panel recently proposed recommendations for medical and mental health care in assisted living and noted that staffing ratios should be acuity driven and related to residents' needs, evidence based as per their associations with quality outcomes, and realistic with regard to staffing shortages.[29] Also, state boards of nursing could allow nurses to delegate unlicensed staff to administer medications, resulting in more health care service provision.[30]

Complexity Of Regulation And The Role Of Government

THE ISSUES Different from nursing homes, which are federally regulated, assisted living is state regulated; states have licensed and monitored assisted living since the 1980s. Variability in assisted living regulations has been the rule rather than the exception, with most states having more than one type of licensure under the broad umbrella of assisted living. For example, Louisiana licenses adult residential care, shelter care homes, and assisted living; at the extreme, New York has forty-five license categories. Also responsive to the growth of ADRD, most states separately regulate memory care services, but not care for the majority of people with ADRD who reside outside of dementia care units, which is a potentially important omission.[27]

In the context of *assistance* and *living*, state regulations may either facilitate or prevent res-

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idents' aging in place or receiving assistance by defining levels of care, scope of services, move-in and move-out criteria, and rules about "behaviors." Such regulations may be necessary if staffing and services are not sufficient to meet residents' needs; indeed, most states allow communities to ask residents to move out if their needs exceed the community's licensing criteria or if the community lacks capacity to provide necessary care. As a case in point, assisted living establishments in Illinois may not admit or retain a resident if the community lacks staff "sufficient in both numbers and skills" to provide mandatory services. That said, some states permit communities to retain residents whose needs exceed scope-of-care rules if residents hire private caregivers or receive hospice services. Data indicate that such opportunities do indeed promote aging in place, in that a higher percentage of assisted living residents have died "in place" in states having regulations allowing third-party services.[31]

Similarly, people might be refused admission or moved out because of specified behaviors. For example, Iowa regulations prohibit assisted living programs from admitting or retaining residents who are sexually or physically abusive or dangerous to themselves or others.[32] Such regulations are consistent with assisted living staff reports that the behaviors most challenging to address are abuse, combativeness, and those that are socially inappropriate.[33] Staff training in how to care for such residents may ultimately promote aging in place. Still, regulations do not fully drive practice. Some communities variably transfer or retain residents with dementia depending on whether managers are on site, the extent to which the culture is dementia friendly, and whether families are involved in care,[34] underscoring the importance of the workforce and the role of families.

POLICY IMPLICATIONS State regulations seek to protect residents and promote high-quality care and outcomes while responding to consumers' expectations. Toward that end, and in light of the limitations of the assisted living workforce, regulators could create more widespread opportunities for third-party services to supplement assisted living care. Currently, only thirteen states explicitly support the use of hospice, private care aides, and home health services across all assisted living license types.[31] However, if regulations allowing third-party services were to become overly stringent or prescriptive—such as dictating the specific type of worker able to provide services—oversight of this complex regulatory arena could become unwieldly. To avoid such a situation, states could expand nurse delegation guidelines in assisted living regulations, which themselves clarify the role of licensed nurses in training and supervising direct care workers. Additionally, partnerships between regulators, private and public organizations, consumers, and others could help refine and strengthen regulation in ways that could benefit residents and staff, a trend that has taken root in Minnesota and elsewhere.[35]

Also, states and assisted living communities could become more active in allowing and using negotiated risk or service agreements between residents, families, and assisted living management. Simply stated, these written documents recognize safety risks posed by a resident's preferred activities, such as activities that constitute a risk of falling or choking, and include the resident's and family's acknowledgment and acceptance of the potential negative consequences of those activities. However, the use of these documents is not straightforward. For instance, there are concerns about whether people with ADRD can complete them if they do not fully understand the risks associated with their choices.[36]

The federal government could promote *assistance* and *living* by coordinating public health activities that expressly include assisted living and by encouraging national uniform data reporting to inform consumers about assisted living. For example, COVID-19 governmental responses expanding telemedicine and restricting visitation were as applicable to assisted living as to nursing homes, and they serve as a model to include assisted living in future public health initiatives.[37] With respect to data and information reporting, federal funding in 2008 developed an assisted living voluntary disclosure tool to inform consumers about numerous key topics, including move-in and move-out requirements.[38] Additional federal support is needed to promote use of the tool and better inform consumers about the processes, services, policies, charges, staffing, and environment of a given community.

Need For Consumer Support, Education, And Advocacy

THE ISSUES Individuals, care partners, and other family members are involved in the decision to seek assisted living, choose the community, and remain engaged after move-in. However, consumers cannot adequately know when it is time to seek assisted living or choose a community if they do not know the *assistance* that is available and the quality of *living* it enables. If such information were available—and if it were standardized and trustworthy—consumers' understanding and expectations would be better informed, and consumers could "vote with their

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feet" for what they need and desire. Thus, consumer support and education could become a vehicle for advocacy and quality improvement.

After a resident moves into assisted living, families generally remain involved in care. They talk to or visit their relative frequently and are significantly more involved in monitoring their relative's health, finances, and overall well-being than are families of nursing home residents.[39] In addition, families are central to informing, guiding, and participating in the care that staff provide for residents with ADRD and to achieving better resident outcomes.[40] In these and other ways, families play a critical role in relation to *assistance* and the quality of *living*. Minnesota's recent effort to involve consumers in creating assisted living regulations and quality guidelines constitutes a model recognizing their importance.[35]

POLICY IMPLICATIONS Because families are an essential component of the assisted living workforce, they could be part of the solution to the workforce crisis if their role as essential workers were recognized through policy and payment.[17] Related models already exist, including state home and community-based care Medicaid programs (that is, assisted living is considered a home and community-based service) and benefits from the Department of Veterans Affairs that pay family members to deliver care.[41–43] In addition, the ongoing National Family Caregiver Support Program funds services that support caregivers, including access assistance, respite care, counseling, and training.[44] These programs and benefits can be vehicles for supporting family caregivers in the care of assisted living residents.

Beyond receiving support, families and care partners must understand the limits of care provision if they are to choose an assisted living setting that meets their relative's needs and preferences. They should be advised to complete negotiated risk or service agreements to *live* with choice; seek advocates such as ombudsmen when *assistance* is insufficient; and serve as advocates to promote *assistance* and *living* when necessary. As sources of information, assisted living community websites are largely used for marketing and are not impartial sources of information. State websites often require sophistication to navigate and include limited information, and internet web searches typically prioritize businesses that pay to promote their organization.[45,46] Unfortunately, the efforts of well-intentioned organizations such as the National Center for Assisted Living, the National Consumer Voice, and the national Center for Excellence in Assisted Living are unknown to most consumers.

Instead, efforts for national disclosure such as that related to cost and care could be renewed,[38] state survey reports could be more readily available, and personalized consumer reviews could be encouraged.[47] Also, consumers should be informed when relevant new information emerges, such as recent recommendations by a consensus panel for improved medical and mental health care in assisted living.[29] Strategies to bring this information to the awareness of consumers, such as the Be Well in AL coalition,[48] could empower them to advocate for better assisted living. In addition, experts should develop recommendations to promote better *assistance* and *living*, akin to the health care recommendations.

It is time to devote attention to ways that would enable assisted living owners and operators to provide care and services in a way that consumers desire.

Lack Of Sufficient Financing And Accessibility

THE ISSUES Older adults cannot be *assisted* and *live* in assisted living without adequate resources to pay for their care. Assisted living evolved from a private-pay model, in which residents and their families paid for assisted living relying on personal savings, retirement accounts, Social Security, pensions, and family members' incomes. Fortunately, there has been growth of public financing for assisted living and thus increased access for lower-income residents. By 2018, forty-seven states covered assisted living services through a Medicaid waiver or state plan amendment;[49] almost one in five assisted living residents were enrolled in Medicaid.[50] Yet access is often limited because of insufficient funds and long waiting lists.[2] Some states now provide funding for assisted living through a state supplemental payment for low-income residents receiving Supplemental Security Income,[51] and the Department of Veterans Affairs provides assisted living benefits for low-income or disabled war-

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time veterans and their spouses.[52]

Although public financial support for assisted living has increased over time to enable access for low-income older adults, there is need to help the "forgotten middle"—middle-income older adults who cannot afford to pay privately for long periods of care but who have not sufficiently impoverished themselves to qualify for government benefits.[53] Even for those who can afford private payment, access to assisted living may be limited if charges include a base fee (such as for housing, maintenance, and meals) and additional charges that increase as the need for assistance increases. Such increases are a common business model in assisted living and can include charges for activities of daily living, medication management, and other services.

POLICY IMPLICATIONS Financing and accessibility can be addressed through various strategies at the federal and state levels. Some assisted living companies have experimented with operator-owned Institutional Special Needs Plans (I-SNPs), a type of Medicare Advantage plan that provides medical and supportive care in assisted living.[54] Also, Medicare Advantage now pays for assisted living services such as personal care and transportation through the new expanded special supplemental benefits for the chronically ill and value-based insurance design.[55] Additionally, several states have proposed a universal long-term care financing program that could extend to assisted living; in 2019, the Washington legislature enacted such a program.[56] Going forward, proposed federal legislation aims to create employer/employee sponsored long-term care catastrophic insurance known as the Well-Being Insurance for Seniors to be at Home Act (WISH Act). Such initiatives would provide middle-income people with funds to cover living and assistance costs in assisted living.

Conclusion

To be clear, today's assisted living does provide *assistance* and enable aging in place with a good quality of *life*—but not for everyone. It has become clear that assisted living is not fully meeting its intentions, especially for residents with fewer resources and more care needs. The reasons are manifold: Residents' needs have progressed from basic support to more complex medical and mental health care, the size and sufficiency of the workforce has become more limited, assisted living regulations have become more complex, the roles of families and consumers have become more important, and financing has restricted accessibility. Appendix 2 summarizes the recommendations discussed in this Commentary.[11]

The US relies on the assisted living sector—the largest residential provider of long-term care[1]—to help the growing older adult population to *live* with *assistance*. This Commentary suggests that it is time to devote attention to ways that would enable assisted living owners and operators to provide care and services in a way that consumers desire: *assistance* in meeting needs combined with the highest achievable quality of *living* through autonomy, flexibility, dignity, and choice. Results from the assisted living natural experiment suggest the need for a concerted effort to purposefully chart the path forward, just as the National Academies of Sciences, Engineering, and Medicine did in their 2020 report on the national imperative to improve nursing home quality.[57]

If not now, when? ■

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