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Assisted Living Facilities: Understanding Long-Term Care Options for Older Adults

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Assisted Living in the U.S.

Assisted living (AL) is a large and growing long-term care residential option for individuals who need or want additional supports for activities of daily living. There are approximately 30,600 AL communities in the U.S. with almost 1.2 million licensed beds and 818,800 residents. This industry employs a total of 478,500 workers, 66% of which are direct care workers (DCWs) (NCAL 2023). These DCWs are the first line of care. AL, though often seen by the public as interchangeable with skilled nursing homes, was built and is regulated as a social model of care. This community-based care is less restrictive and strives to be home-like.

AL typically offers 1) 24/7 availability of supervision, 2) exercise, health, and wellness programming, 3) housekeeping and maintenance, 4) meals and dining services, 5) medication management or assistance, 6) personal care, and 7) arranging for transportation (NCAL 2023). This differs from nursing home care in that there is no promise of 24/7 access to medical services or constant supervision.

AL residents vary greatly in the amount of care they need from person-to-person (Kistler et al. 2017). Some AL residents are spouses who live with their partners whose care needs have become too great but are themselves much more independent. Some move into AL communities to support medication management, housekeeping and cooking and need little other support.

Rising acuity levels, meaning the average AL resident has increasingly more health conditions and functional limitations, do mean that as residents age in place, they likely require more health services. While these services could overlay AL services, much like they would if the person needing care was living at home, these are not provided by AL communities. These health care services include primary care, home health, physical and occupational therapies, and hospice and often are performed by contracted providers, sometimes associated with the AL and sometimes contracted or arranged by the resident's family. The haphazard growth of this model and the tensions inherent have spurred calls for Assisted Living to be reimagined (Zimmerman et al. 2022).

Assisted Living Residents

About half of AL residents are over the age of 85, most are women (70%), about three quarters are not married and about 90% are White. Most AL residents need help with medications, and more than half need help with three or more activities of daily living such as bathing, dressing, or toileting (NCAL 2023; Kemp, Ball & Perkins 2019). AL residents depend on their care networks, a constellation of kin and non-kin involved in resident lives such as friends, neighbors and church or other community members, to arrange medical care, provide social support, coordinate care, engage residents in activities, and bring needed supplies such as medications, favorite snacks, health and beauty items, and incontinence pads. These care networks also play an important role in advocating for residents and negotiating care with AL staff (Kemp, Ball & Perkins 2013; Kemp et al. 2018; Kemp 2021).

Many residents living in AL have dementia. While the average older person living with dementia lives between 4 and 8 years, they can live 20 years or more (Alzheimer's Association 2023). About 42% of AL residents have a dementia diagnosis (NCAL 2023) but we can assume this is underreported as many older adults are not screened, tested, or diagnosed with dementia despite showing symptoms in memory, thinking, or making decisions that impact everyday activities.

The variability in symptoms and experiences is part of what makes people living with dementia so difficult to care for. Like all people with chronic disease, people living with dementia have good days and bad days. Person centered dementia care is needed to tailor care and support to individuals in ways that account for preferences, life experiences, communication styles and support needs that change over time (Fazio 2018). People living with dementia experience stigma and often become isolated. Residential care is an important option for combatting social isolation and exclusion often experienced by people with dementia and their care partners (Nguyen & Li 2020).

Assisted Living is an Important Long-Term Care Option

AL, unlike nursing home care, is almost entirely private pay. Only 18% of residents rely on Medicaid to pay for daily services (NCAL 2023). Most of these residents are very low income

and qualify for state Medicaid waiver programs that exist in 41 states and that often have waiting lists. According to NCAL (2023) the average monthly cost of AL is $4500. As such, AL is inaccessible to most Americans. Yet, on the spectrum of long-term care, it is often needed. Seen as a step of care between unpaid care by loved ones and nursing home care, AL provides an important long-term care option. When the care needs of a loved one exceeds the capacity of their care network, the person needing care and their unpaid care partners are forced to manage. This is often after an event. This event could be a hospitalization, a fall, a report of self-neglect, an unsafe situation, loss of driving ability or maybe mismanaged finances or medications.

Sometimes, after a hospitalization or after insurance-supported inpatient rehabilitation care, discharge planners help individuals with very high care needs find nursing home placement. If that doesn't happen, the care network is forced to navigate, with little support or education, a variety of options, none of which are usually covered by health insurance. If they have significant financial resources, AL is a useful and attractive option. If not, managing the care situation means that care partners reduce working hours, build precarious care or financial arrangements across families, hire piecemeal personal care support or simply cross their fingers and hope things turn out okay. Given the geographic dispersion of today's families, the lack of affordable residential care options often leaves American families in tough situations.

Assisted Living and Persistent Workforce Challenges

Sixty-six percent of the AL workforce are "aides" or direct care workers (DCWs) (NCAL 2023). DCWs in AL and across long-term care are predominately women, people of color and disproportionally immigrants (PHI 2022). The typical direct care worker in AL makes about $15 an hour, works 36 hours week in AL, and works for a for-profit company. About half have health insurance through their employer and about 22% get health insurance through Medicaid or another means tested program. About half live under 200% of the poverty line with household income at about $46,000 (Kelly et al. 2020).

DCWs also face dangerous working conditions, persistent occupational segregation, have limited access to paid leave, and experience very little career advancement (Dill & Duffy 2022;

Dill et al. 2022). As stated by Scales & Lepore (2020) "[direct care work] requires a mix of technical caregiving skills; health-related knowledge; infection prevention and control expertise; emotional intelligence and relational skills; and problem-solving and decision-making abilities, among other competencies (p. 173)." Despite highly meaningful jobs with high intrinsic rewards, the lack of extrinsic rewards including compensation, drive turnover (Dill, Morgan & Marshall 2013; Morgan, Dill & Kalleberg 2013). Turnover rates in long-term care have been persistently slow to recover since the start of the COVID 19 pandemic and the recovery has been most difficult for women and people of color (Frogner & Dill 2022). In this context, the use of agency staff, or those that are temporarily hired from staffing agencies to fill staffing shortages, has remained persistently high. Use of agency staff makes relationship-based, person-centered care difficult. Many organizations have reduced the number of new residents because they do not have the staffing to accommodate them despite having available licensed beds. More than sixty percent of AL facilities have moderate to high staffing shortages (NCAL 2022).

Assisted Living Context and Pressures

While the scope of abuse and neglect in AL facilities is unknown, several media reports have called attention to severe cases of neglect and mistreatment and the significant and surprising out-of-pocket costs that face older adults as they age in AL (Teegardin 2019; Rowland et al. 2023; Rau 2023). Abuse and neglect of our Elders and people with disabilities is unacceptable and is far too prevalent. I will say, though, in our hundreds of interviews with DCWs and other staff across the sector, I have met no "bad actors." While there are "bad actors" in all industries who are actively seeking to harm others, it is my experience that DCWs and AL staff go to work wanting to do the best they can, engage in meaningful relationships with their residents and promote their health and wellbeing. AL workers, like most direct care workers, tend to go into this line of work to give back, to make a difference, because they value Elders or because it is a calling for them (Kemp et al. 2010).

Unfortunately, the system we've set up works against them. DCWs working in all long-term care settings experience low wages, few benefits, heavy workloads, dangerous jobs, and little to no career mobility. These DCWs are managing heavy workloads with unrealistic expectations of what they can get done in one shift, put themselves and their families at risk of

infectious disease, are called on to do heavy emotional labor, often managing multiple jobs to make ends meet and many are experiencing burnout after the multiple personal and collective traumas experienced during and after the pandemic. For a group that was already vulnerable, these workers faced grief, uncertainty, risk, high unpaid care demands and high work demands, and mental health needs that go largely unaddressed.

For AL management and owners, there is pressure to take or keep residents with high levels of acuity. Filling beds is an imperative to cover staffing costs and now rising agency staffing costs. Well-resourced families would rather have mom in a home-like or hotel-like AL rather than an institutional nursing home if given the choice.

We gerontologists advocate for aging in place so that older adults can create home and have familiar settings in which to age well. This supports autonomy, meaning-making, relationship-building and also supports people living with dementia to be in familiar settings to support their cognition. As a social model of care, the walls of the AL building are permeable. People go for walks, sign in and out, go visit families and go on outings. This engagement with the community is vital to the well-being of AL residents (Ciofi, Kemp & Bender 2021). Overworked staff, lack of documentation, lack of meaningful oversight, higher acuity levels, lack of communication, and haphazard care coordination mean that residents are vulnerable without these wrap-around supports.

The tiered fee structure for additional services many Assisted Living communities offer, corresponds to the needs of residents and the need for providing additional staff to support those residents. Transparency in how those fees are determined and what impact they have on support for the residents who pay those premiums is certainly lacking. We know that 24/7 nursing home care and home health care are both, on average, more expensive than AL. The vast majority of AL services are private pay making it very difficult for residents and their care networks to plan for and understand how charges change over time.

Inconsistent Staffing and Training Requirements in AL

The AL direct care workforce is comprised of DCWs who are certified or registered (e.g., certified nursing assistants (CNAs)) and those who are not (e.g., personal care aides). AL

communities make a choice between hiring CNAs, whose training and competency has been assessed by the State, or personal care aides with little to no formal training (Kemp at al. 2010). The CNA training is monitored by the state agencies responsible for facility licensure. Each state agency reviews CNA training programs for quality and state registries allow employers to verify credentials of DCWs who have completed this training and provide employers data on whether there are any outstanding complaints on file for a particular worker (Kelly et al. 2020). While many AL communities choose to hire CNAs, they lack this minimal oversight for initial training provided staff. In terms of initial and continuing education, states have sizable variability in the topics required (e.g. role of the PCA, consumer rights, ethics, and confidentiality, health care support, infection control) (Kelly et al. 2020). Several states have recently added training requirements for DCWs in AL, particularly in terms of dementia education, but these are generally loosely written and enforced with minimal oversight by state regulatory bodies.

Monitoring and Enforcement of Quality of AL

Monitoring and enforcement of quality of AL by states is inconsistent and not transparent. Kaskie et al. 2022, from their survey responses of state administrative agents, show that in half the states, monitoring and enforcement oversight of AL was dispersed across three or more agencies, staffing levels and budgets varied greatly. Fewer than 10 of the states shared information about their monitoring and enforcement procedures in a way that would be publicly accessible. Forty-five states conduct inspections at the time of licensure, 39 conduct annual or biannual inspections and only seven require AL facilities to submit an annual report (Kaskie et al. 2022).

A Mindset Shift is Needed

In her book, *Disrupting the Status Quo of Senior Living: A Mindshift*, Jill Vitale-Aussem (2019) lays out what I think is the crux of the problem facing senior living. AL is marketed to those who can afford it with a hospitality mindset. They advertise and compete on the basis of amenities, beautiful campuses, luxury food and furnishings, and concierge services. This model encourages residents and families to think about living in AL buildings as though they are going to a hotel or resort.

In reality, this framing, where residents are the guests and staff are encouraged to cater to their whims, increases what Dr. Bill Thomas of the Eden Alternative calls the three plagues of long-term care - helplessness, boredom and loneliness. By encouraging passivity, we leave residents with few opportunities for giving back, participating in the community or creative pursuits (Basting 2020). Instead, long-term care that is person-centered, community-minded and empowering has a much better chance of meeting the needs of residents, staff and care partners.

Person-centered care means that the person receiving care is in the driver's seat, to the extent they are able and for as long as they can. Ideally, the resident sets the goals of care collaboratively with both unpaid and paid care partners. Person-centered care practices have been associated with improved quality of life and quality of care for residents (Fazio et al., 2018; Poey et al., 2017). Shifting from a hospitality to a community mindset means that residents and the entire care network are valued members of the AL community. This shift encourages relationship building, transparent communication, interdependence and the promotion of citizenship where all members of the community have a role in improving quality of life. An open community mindset would also improve the safety culture of an AL by promoting communication, relationships and empowering all members to look out for one another.

Empowerment of residents and their care network is also vital to moving this sector forward. For residents, it's truly engaging them in their own care, using a strengths-based approach where individuals are supported to do as much for themselves for as long as possible no matter how slow the process (Yan et al. 2023). For workers, particularly DCWs, it is more complicated. Empowerment for workers means that we listen to, respect, pay, include, collaborate with, provide for the safety of, educate, and ultimately professionalize the workforce (Morgan and Ahmad 2023). The persons (e.g. resident, staff, care partner), not the task, is what we attend to first. This means that workers have the job quality they need to be whole and happy individuals who can then have the space in their work to be creative and engaged problem-solvers in the community. Empowerment for unpaid care partners includes education

on dementia, support to continue to engage and support their loved one and an open invitation to be part of the communities in which their loved one resides (Kemp 2021).

Recommendations

- **Support standardization of monitoring and resources to increase state-based oversight and transparency** Standardizing state transparency and oversight supports public awareness of the industry and promotes the ability of potential residents and their care networks to make informed decisions.
- **Improve and standardize initial and continuing education training for DCWs in AL** This should include realistic job preview, interactive and engaging onboarding with peer mentorship and check-ins over the first three months, a training registry that supports both initial and ongoing training and promotes portability, stackability, and career progression. Training requirements should emphasize person-centered dementia care, meaningful engagement, living well with dementia, strength-based approaches, trauma-informed and self-care, communication skills, and non-pharmacological approaches to dementia care. See https://aging.georgia.gov/sites/aging.georgia.gov/files/GARD%20Competency%20Guide_PDF.pdf
- **Professionalize the direct care workforce** This strategy needs to be engaged in collaboration across long-term care sectors. This is one workforce that moves between and across sector lines constantly. Professionalization includes: occupational credentialing that acknowledges competencies of incumbent workers, ties competency accrual to significant and meaningful career lattices that have transparent wage increases, credentialing that is stackable and leads to higher order credentials that support key areas of need including meaningful engagement of residents, person-centered dementia care, strength-based creative expression outlets (e.g. music, drama, arts, expression), health and wellbeing, trauma-informed approaches, and documentation and quality improvement practices.

- **Incentivize and reward good employers who deliver high quality care.** Employers can make incredible differences in the lives of their workers and residents and curb turnover and improve recruitment by enhancing hiring practices, increasing compensation, enhancing benefits, improving orientation and onboarding, increasing access to education and training and expanding career opportunities (See short micro-learning videos on these topics: https://www.youtube.com/playlist?list=PLXNnxuyRl8NQHl5kx6ukHxVHac_VjOCyn)
- **Increase access to AL** Efforts should be made to increase affordable long-term care residential care options for middle class and working-class American families. This should include education about long-term care options, investment of resources in creating tools for navigating and making informed decisions about long-term care options, and incentives to develop and test inclusive models for rebalancing long-term care in ways that provides high quality care and system savings.
- **Improve care coordination and resources for people living with dementia and their care partners** People living with dementia occupy many long-term care spaces. Regardless of space, they deserve high quality and coordinated care. People are not simply a diagnosis and holistic and integrated care approaches are possible and needed to support the growing number of people with dementia and their care networks. Models such as the GUIDE model (https://www.cms.gov/priorities/innovation/innovation-models/guide) have great potential to provide holistic care to people with dementia and their care partners in ways that reduce stigma, coordinate care, improve outcomes and provide needed supports for all involved.

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