The Imperative to Reimagine Assisted Living

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Special Article

The Imperative to Reimagine Assisted Living

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Abstract

Assisted living (AL) has existed in the United States for decades, evolving in response to older adults’ need for supportive care and distaste for nursing homes and older models of congregate care. AL is state-regulated, provides at least 2 meals a day, around-the-clock supervision, and help with personal care, but is not licensed as a nursing home.

The key constructs of AL as originally conceived were to provide person-centered care and promote quality of life through supportive and responsive services to meet scheduled and unscheduled needs for assistance, an operating philosophy emphasizing resident choice, and a residential environment with homelike features. As AL has expanded to constitute half of all long-term care beds, the increasing involvement of the real estate, hospitality, and health care sectors has raised concerns about the variability of AL, the quality of AL, and standards for AL. Although the intent to promote person-centered care and quality of life has remained, those key constructs have become mired under tensions related to models of AL, regulation, financing, resident acuity, and the workforce.

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These tensions have resulted in a model of care that is not as intended, and which must be reimagined if it is to be an affordable care option truly providing quality, person-centered care in a suitable environment. Toward that end, 25 stakeholders representing diverse perspectives conferred during 2 half-day retreats to identify the key tensions in AL and discuss potential solutions. This article presents the background regarding those tensions, as well as potential solutions that have been borne out, paving the path to a better future of assisted living.

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What is now known as assisted living (AL) had its roots more than 80 years ago, evolving in response to older adults' need for supportive care (but not ongoing nursing care), and distaste for nursing homes and older models of congregate care. As it expanded with involvement of the real estate, hospitality, and health care sectors, concerns about the variability of what was considered “assisted living” arose, along with concerns related to quality and standards. Using today's common definition of AL as 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, there are 996,100 licensed beds in 28,900 AL communities across the United States, ranging in size from 4 to 581 beds (average 35 beds).

Intending to promote person-centered care and quality of life, the key AL constructs as originally conceived were supportive and responsive services to meet scheduled and unscheduled needs for assistance, an operating philosophy emphasizing resident choice, and a residential environment with homelike features (Figure 1). As AL has expanded to constitute one-half of all long-term care beds, the intent to promote person-centered care and quality of life has remained, but those key constructs have become mired under tensions related to models of AL, regulation, financing, resident acuity, and the workforce (Figure 2).

Many stakeholders agree—and vehemently so—that today's AL is not as intended in the past, and that it must be reimagined for the future. Toward that end, 25 stakeholders representing diverse perspectives (see author affiliations) conferred during 2 half-day retreats to identify the key tensions in AL and discuss potential solutions. As will become clear, the choice of Venn diagrams to display these tensions illustrates their overlapping nature and suggests the complexity in achieving the desired future.

Current Tensions in Assisted Living and Potential Solutions

Assisted Living Models

Tensions

Some of the earliest models of AL date to the 1940s in the form of board and care homes. Between roughly 1980 and 2000, 3 key events shaped AL: a growing distaste for nursing homes and idealistic values regarding alternative settings; recognition of different types of AL (eg, hospitality, health care); and apparent dilution of ideals during a
As the field grew, so too did concern about the variability and quality of AL, and with it pressure to more clearly define AL. In response, a 2001 hearing of the US Senate Special Committee on Aging resulted in a workgroup of 49 national organizations tasked with developing guidelines for AL policy, regulation, and operation. The 2003 report of the Assisted Living Workgroup included 131 recommendations to promote quality in AL, with guidelines for federal and state policy, state regulation, and operations. It included a 3-part definition of AL, focusing on services and regulation (state regulated to provide personal, health related, and other services), private units (shared only by choice), and levels of care (at least 2 levels based on resident need), but was unable to obtain consensus agreement on the definition. Opponents pointed out that health-related services were ill defined, that wealth to afford private units should not limit access, and that there was no evidence that 2 or more levels of care were important to quality.

Absent common agreement, models of AL have continued to evolve based on what developers have offered and states have regulated. Some models have been differentiated based on initial key constructs of AL (resulting in 4 models of low/minimal privacy and service, high privacy and low service, high service and low privacy, and high privacy and high service); how they were regulated as states began licensing settings and services (3 models including institutional board and care (allowing multiple occupancy rooms and shared bathrooms), housing and services, and purely service oriented); and also reflecting the residents they serve using empirically identified criteria that differentiated 193 diverse AL communities across 4 states (5 models of impairment oriented [residents require help in transferring], dementia oriented, mental illness/Medicaid oriented, structure and process oriented [older, high privacy, strict admission criteria], and a mixed model [which did not vary significantly from others in terms of resident case-mix or structures or processes of care]). Notably, although state regulations dictate different licensure categories, the 5 models did not separate around state lines. AL communities do not market themselves in accordance with these or other models, however, and their leadership may not even be aware of nor embrace such models; more so, none of the models have been compared with each other. The fallout is that consumers also are generally not aware of differences as they review AL options, nor have they learned about differences in advance of having to make a time-sensitive decision.

Given variation across models, another concern is that AL communities may not provide the services that residents want or need. In cases where they do offer meaningful choice from an appropriate range of services, the intersection in Figure 1 (person-centered care and quality of life) may be realized. However, the reality is more often that the areas do not fully overlap. In addition, concern has been raised about the scale of large AL communities and those that are not local in feel, insofar as they may focus more on the building than on the person, such as by not being sensitive to resident preferences, limitations, or cultural heritage.

Because some stakeholders consider there to be a dichotomy between the “social” and “medical” model of care—despite the fact that a social model is not antithetical to health care—an ultimate question has become whether AL is and should be a “social model” of care. Given that the Assisted Living Workgroup specifically referenced health-related services, it does not seem that AL ever intended to ignore residents’ health needs; instead, the model has not developed
wide-scale strategies to integrate such services. Today, experts and organizations recognize the need for a holistic blended model that includes social and medical elements, especially as resident acuity has increased.10–12

Potential solutions

The variability of AL has made consumer education critical. Organizations including Argentum and the National Center for Assisted Living provide information about AL on their websites, as do an increasing number of states and AL communities themselves (especially those that are part of chains).13 Unfortunately, this information does not sufficiently differentiate communities, in large part due to definitional inconsistencies and inadequate information. Standardized public reporting could overcome this challenge, and an effort supported by the US Agency for Healthcare Research and Quality went so far as to develop a standardized “disclosure” tool that, if used, would allow consumers to compare communities on areas including the move in/move out process, service provision, policies, charges and payments, staffing, and the environment.14,15 The beauty of such a tool is that it educates consumers about the range of important areas around which AL communities may differ, both across and within states.

Further related to models, it has been suggested that decoupling services from housing, which has been done by some states, may enable more individualization and innovation. Having more of a tenant-landlord arrangement may not only allow residents to better choose the care they receive, it also may sidestep some of the non-person-centered practices that have become common in AL (eg, providing care at times of staff convenience).16 The state of Connecticut embraces such a model in that it licenses and regulates AL service agencies as opposed to the community.17 Proponents of decoupling stress that the services should drive the housing, rather than the housing driving the services. The Program of All-Inclusive Care for the Elderly (PACE) has already demonstrated that PACE services can be provided to participants who reside in AL, as can adult day services; in so doing, these services augment the capacity of the AL community.18 A robust example of a housing with services program has been implemented by 2Life Communities in the Boston area, which among other services, coordinates care and data sharing with health insurers.19,20

Intuitively, one might surmise that smaller models of AL are able to promote more resident control, autonomy, and person-centered care, but the literature is mixed in this regard.21 Residents in larger communities have reported feeling more at home than those in smaller communities,22 yet both larger and smaller communities have been associated with greater resident autonomy.23,24 However, resident case-mix differs by AL size (eg, smaller communities house more younger residents, residents receiving Medicaid, and with dementia, depression, and functional care needs), and larger communities have more staff, meaning that size comparisons may be influenced by these and other differences.25,26 Thus, proposing a solution strictly on the basis of AL size is not person-centered.

Ultimately, understanding which models are best for what residents lies in evaluation, making side-by-side comparisons, allowing for resident preferences and adjusting for resident differences, recognizing that outcomes related to one valued state (eg, safety from harm) may conflict with outcomes related to another valued state (eg, autonomy).27 In nursing homes, quality measures are largely medical and health-related outcomes, whereas in AL it is recommended that they address quality of life and satisfaction, along with staffing, safety, health outcomes, and care integration; many such measures have been critiqued and compiled for AL, including an AL-specific measure to assess person-centeredness.28–30 If AL quality measures include both social and health components, perhaps the “social model/medical model” dichotomy will be put to rest.

**Assisted Living Regulation**

**Tensions**

If quality were not an issue, there may be no need for regulation—albeit recognizing that regulations set the floor rather than the ceiling for expected care. In nursing homes, many stress the need for regulation to assure quality, yet disdain the survey process itself.31 In sum, experts support long-term care regulations at the same time they are dissatisfied with them, including in AL.13 States began implementing AL policies in the late 1980s, and over the next 30 years (by 2019), more than 2250 AL regulations consistent with the recommendations of the Assisted Living Workgroup were in effect. That said, not all regulations reflect the intentions of the Workgroup, and as new concerns have emerged (such as insufficient diversity, inclusion, and medical care) or become more important (such as quality programming and dementia care), states have not kept pace, often resulting in outdated or inadequate rules.12

Given the complexity of AL, variable models, and evolution over time, the AL regulatory arena is complicated. States have 182 AL license classifications representing 45 primary licenses, 71 subtypes, and 66 designations that regulators can combine in 350 different ways.32 Beyond these classifications, AL operators must also respond to multiple federal policies, such as those set forth by the Fair Housing Act, the Centers for Medicare and Medicaid Services (CMS), the Nurse Practice Act, and the Americans with Disabilities Act. In addition, financial underwriters and insurers might require policies that exceed state rules (eg, related to nurse staffing) or that are not well defined by states, such as negotiated risk agreements.33,34

Affordability poses another regulatory challenge. AL developers focus on older adults with at least $62,000 in annual income (at times including their children’s financial support), which is needed to afford AL and health-related expenses, yet the middle-income senior population will nearly double by 2029, and 54% will lack financial resources to afford AL.35 Catering to this sector, affordable development and operating sources such as low-income housing tax credits and Medicaid waivers often require or prohibit specific physical and operational elements (eg, private apartment units), even when state regulations do not. In sum, the tension is that some options intended to promote accessibility may run counter to state regulations.

Also apparent in regulations is reference to the social model of care, emphasizing resident autonomy, dignity, and choice.2 Tensions exist between resident choice and rules designed to support safety. For example, Florida regulations do not permit AL communities with a “limited nursing services” license to care for residents with a stage 3 or 4 pressure ulcer even if they would choose to stay, despite evidence regarding negative outcomes associated with care transitions.36,37 Discussion of negotiated risk agreements in AL date back to the 1990s, but a providers’ hands may be tied if the regulations are not flexible.40 In such an instance, person-centered care is challenged.

Potential solutions

First and foremost, if regulations are to promote quality care while being responsive to consumer preferences, they must be created in partnership between regulators, AL leaders, residents and their advocates, and other stakeholders, and routinely assessed to ensure that they are consistent and nonduplicative, that they leave no major gaps or loopholes, and that they are updated as needed to reflect emerging issues. By way of example, 5 states have public-private partnerships to improve AL quality and inform consumers: 3 require mandatory quality reporting (Ohio, Minnesota, Oregon), and 2 are voluntary programs (New Jersey, Wisconsin). These states collect and report resident and family satisfaction measures; some also collect quality metrics associated with person-centered care, resident falls, antipsychotic medication use, and staff training and
Assisted Living Financing

Tensions

As AL communities evolved, so too did business models that finance their development and operations. Typically, AL consists of real estate (housing) and service components. A community may be owned and operated by a single entity, or the service component may be managed by a provider leasing the real estate. More than one-half of AL communities are chain-affiliated; in nursing homes, concern has been raised about the impact of chain ownership on staffing and quality, and although findings are not conclusive, similar questions may be relevant for AL.

Charges for AL housing and services are largely paid by residents’ incomes and assets (on occasion with family supplementation), and they are notable. Per month, the median AL cost is $4300, ranging from an average of $3000 in Missouri to $6690 in Delaware. Annually, median costs increased 79% between 2004 and 2020—from $28,800 to $51,600. This rate of increase is well in excess of nursing home and home care costs (62% and 30%, respectively), and has far outpaced US inflation. The only source of insurance covering AL is long-term care insurance, but the proportion of older Americans covered by such insurance remains small; in 2018, it paid for approximately 36,000 claimants residing in AL. In terms of other payment sources, almost 20% of Medicare beneficiaries residing in AL are dually eligible (ie, also eligible for Medicaid), but while virtually all states cover some AL service costs through Medicaid, access is often limited due to waiting lists and insufficient funds. Further, the generosity of state payment varies widely; in 2014, annual per beneficiary Medicaid spending on AL services ranges from less than $2000 in North Dakota to more than $100,000 in Pennsylvania.

AL costs highlight that investors and operators have largely focused on the senior market at the upper end of the income distribution. However, the fastest and the largest growing segment are middle-income seniors whose financial resources are projected to be below expected annual AL costs. Fragmented payor systems impact an individual’s ability to choose where, when, and how to receive services and supports. The financial future of AL may, therefore, depend on finding less costly ways to serve this “forgotten middle” market and expand access for low-income older adults.

Potential solutions

AL owners and developers may consider different approaches to lowering costs, perhaps by refitting existing structures rather than undertaking new and increasingly expensive construction—although bringing existing structures up to code may itself be prohibitively expensive. Alternately, some have suggested diversifying housing options and modifying services to lower monthly cost. Owners and operators may be willing to consider this strategy if it prevents residents from having to move out as their resources deplete, or if it expands the AL market by allowing the growing “forgotten middle” to move in. Residents and staff should be involved in planning renovation and new construction, and evidence-based design should inform the use of the physical space and technology infrastructure to support quality of life and staff efficiencies.

To stimulate innovation, it may be possible to offer AL owners and operators local, state, and federal tax incentives and direct public subsidies if they increase access for middle-income residents. Further, if AL can be shown to delay or reduce nursing home placement and spend-down to Medicaid, such incentives may generate good public return. However, the risk of developing options for the middle market is that these individuals are more likely to deplete their funds and become Medicaid eligible (although less quickly than if they were paying for round-the-clock home care), in which case lower cost options and operational efficiencies will be necessary to allow them to stretch their resources. One example of an incentive to address the affordability gap is Lifesprk, an organization that links housing, primary care, care coordination, and financing in novel ways, including through a new CMS payment model called Global and Professional Direct Contracting.

About 35% of Medicare beneficiaries residing in AL are enrolled in Medicare Advantage (MA) plans. Their enrollment opens an opportunity, especially for larger AL communities, to partner with existing MA plans or develop their own plans such as to provide on-site medical services. Increased care coordination and monitoring may translate into fewer hospitalizations, thus delaying or preventing individuals from moving to a higher level of care. Some AL operators have started to experiment with such partnerships, but they remain untested and marginal. Other partnerships may involve making Special Needs Plans available, for example to residents with dementia, or partnering with PACE, both presenting opportunities for residents to age in place and to expand to new and lower-income markets.

From a Medicaid perspective, doing away with state AL waiting lists and coverage limits would be a first step in promoting equity for Medicaid eligible AL residents and more fully including AL in states’ long-term care rebalancing policies. Promoting equity requires that quality for Medicaid recipients be similar to that for private pay residents. Furthermore, broadening eligibility and expanding coverage to home and community-based services for individuals with less acute care needs may prove to be cost-effective for Medicaid by delaying or preventing nursing home admission.

Assisted Living Residents

Tensions

AL models, regulations, and financing must account for the rising functional, medical, and mental health care needs, as well as sociocultural preferences, of AL residents. The resident population now living in AL has been likened to those in nursing homes. Rates of chronic illness in AL are roughly one-quarter to one-half the rate of chronic illness among nursing home residents, and perhaps not surprisingly, 24% of residents are hospitalized each year. In response, some state Medicaid programs provide service coverage to residents with nursing home level of care needs. Similar to the challenges with AL regulations, however, the definition and measurement of this level of need varies across the states. Further related to diversity,
although today 81% of residents are White and non-Hispanic,3 AL operators will need to be responsive to an increasingly diverse population, including variation in race and ethnicity as well as sexual orientation and gender identity.

Nationally, 52% of AL residents are age 85 years and older; between one-third and almost one-half have arthritis or heart disease, and 42% have dementia or moderate/severe cognitive impairment.46 A majority require help with activities of daily living, most commonly taking medications (87%), bathing (64%), walking (57%), and dressing (48%).67 In addition, the mental health care needs of AL residents are notable and rising; 31% are diagnosed with depression and more than 11% have serious mental illness.7

Typically, AL has limited ability to meet the needs of higher-acuity residents due to off-site medical care, ineffective segregated memory care units, low staffing ratios, and insufficiently trained staff—all pointing to a disconnect between the current system and residents’ needs.68,73–76 To further complicate matters, as AL communities are called upon to address higher resident needs, they are simultaneously tasked with straddling the delicate balance between acuity, safety, and autonomy, and at the same time face liability for the well-being of increasingly medically complex residents.75

Potential solutions
AL residents are typically treated by community-based medical providers who rely on families or staff to contact them when problems arise. This arrangement is challenging for older adults who are ill, for families who live at a distance or must secure transportation, for staff who rely on a prompt reply from providers, and for providers who rely on staff to convey health-related information.77 Given rising resident acuity, it has been suggested that AL embrace models that coordinate and/or integrate health and long-term care services, or that (as above) AL become the housing with service subcomponent of a coordinated care system where a separate enhanced care management program coordinates primary care, ancillary services, and therapies (such as Georgia’s SOURCE Medicaid Waiver program).78 Although potentially attractive, integration is challenging due to a lack of infrastructure (eg, electronic health records), a private pay model that precludes shared savings from reduced Medicare costs (if, for example, integrated care avoids hospitalization), and the very fact that models of AL have stressed quality of life and avoided medicalization.61 However, the COVID-19 pandemic may well change attitudes toward the need for health care in AL, given an excess mortality rate of 17% during the pandemic,79 a 4-fold higher case fatality rate among AL residents than during the same period of the pandemic; the separation that is beneficial, but instead the approach to care.93 Mostly, it has been pointed out that there is nothing special about (segregated) special care, with 2 systematic reviews pointing out that best practices are more important than a specialized unit.94 At the same time, it must be acknowledged that persons without dementia may not want to reside alongside those with moderate or severe dementia, thus underscoring the ongoing dilemma.90 One solution herein is to train all AL staff in dementia care practices, such as those recommended by the Alzheimer’s Association that are setting neutral.96

Diversity and inclusion are emerging policy and professional topics in AL. A few states (California, Oregon, Massachusetts) require staff training in lesbian, gay, bisexual, transgender, and queer (LGBTQ) topics,97 and some providers have adopted culturally and linguistically responsive practices in recognition of current and prospective residents who are diverse in terms of race, ethnicity, culture and sexual orientation. For example, Forbes recently profiled LGBTQ-friendly housing in multiple states and numerous professional associations have developed tools for promoting cultural responsiveness and inclusion.97 More so, if AL is to become more accessible to low-income older adults, care must reflect the needs of this population. Currently in AL, Medicaid residents are more likely to be non-White, younger, male, and never married; to have mental illness or intellectual and developmental disabilities; and to exhibit behaviors such as being verbally or physically abusive.85

Assisted Living Nurse and Direct Care Workforce

Tensions
At its core, the quality of all long-term care is driven by the workforce, and similar to the rest of long-term care, the AL industry is challenged by workforce issues that have become exacerbated since the pandemic. A recent survey found 59% of AL communities reported their workforce situation being worse than it was in 2020, and 81% had staffing shortages they were unable to fill.98 As is true of the entire field of long-term care, these challenges are fueled by low wages, insufficient benefits, poor supervision, strenuous workloads, poorly designed job roles, limited career advancement opportunities, and stigma (eg, perceptions that the staff are not qualified to work elsewhere, microaggressions), among others.99–102 This tension is especially critical because staffing is 1 of the 3 highest costs for AL, along with mortgage/lease payments and food. There are limited evidence-based best practices to recruit and retain direct care staff in AL, and so there is need to better understand what mechanisms attract staff and promote retention, and how related strategies might differ from those in nursing homes.103

Some staffing tensions are more specific to AL, including variable staffing ratios, skill mix, and training requirements. The most common staffing ratio model in AL is flexible/as needed staffing, defined as a “sufficient” number of staff adequately trained to meet residents’
The sufficiency of staffing may be an arbitrary judgment however, and has been challenged in class action suits charging that AL staffing does not meet residents’ needs. \(^{105}\) Skill mix is similarly variable and potentially contentious, with effects on resident outcomes. Slightly more than one-half of AL communities (54%) have a registered nurse (RN) or licensed practical nurse (LPN) on site,\(^ {69}\) and they work within different models of care (no/minimal hours worked by nurses, low hours/primarily LPN, low hours/primarily RN, and high hours/mix of RN and LPN).\(^ {106}\) Although having a nurse on site may reduce affordability, it also may reduce the likelihood of hospitalization or discharge to nursing homes (although findings related to discharge are inconsistent).\(^ {46,107,108}\)

Another key area of variability and tension is training of direct care workers. The regulations of 40 states require staff training, but the number of required hours ranges from 1 to 80; more so, some states are silent as to the topic of training, while others specify the training topics.\(^ {104}\) The adequacy of training is important not only for care provision, it also improves staffs’ own attitudes and satisfaction.\(^ {109}\) Dementia training may be especially important, given the high rate of dementia in AL (42%) and the fact that resident tenure is almost two years (median of 22 months), meaning that the quality of the relationship between staff and residents is especially consequential.\(^ {110}\)

### Potential solutions

Addressing workforce challenges in AL requires many of the strategies being promoted for the long-term care workforce in general: inadequacies in pay and benefits must be rectified, supervision must be improved, workloads must be right-sized, jobs must be redesigned to offer satisfaction and empowerment, and career trajectories or advanced direct care positions must be developed.

Initial and ongoing training needs must also be addressed, especially considering the rising acuity and evolving needs of AL residents. If the training requirements for AL staff are made more rigorous, the workforce might become more professionalized, impacting recruitment of new staff and quality of care for residents. LeadingAge has taken this suggestion one step further by calling for competency-based training requirements.\(^ {111}\) Of course, introducing such standards in AL would require that core competencies be explicated, which has yet to be done. States including Florida and Wisconsin have developed training materials and registries to track required and supplemental training activities for AL, and some universities, including Rutgers, have forged partnerships with AL communities to build the workforce.\(^ {112–114}\)

### Implications for Practice, Policy, and Research

The central tenets of AL—services that are supportive of and responsive to care needs, an operating philosophy emphasizing choice, and a residential environment with the features of home, all combining to provide person-centered care and promote quality of life (Figure 1)—have taken a back seat to tensions inherent in models of AL.\(^ {2,42}\) Dementia training may be especially important given the high rate of dementia in AL (42%) and the fact that resident tenure is almost two years (median of 22 months), meaning that the quality of the relationship between staff and residents is especially consequential.\(^ {110}\)

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the benefit of coordinating health care and reconsidering segregated care; and strengthening the workforce includes training and establishing acuity-based staffing recommendations. Indeed, there is need to understand which models are best for what residents, how regulatory requirements support or hinder evidence-based practice and quality, which financial incentives most efficiently increase access to AL to allow for a more diverse resident population, how to staff acuity-based staff to allow for a more diverse resident population, how to properly address resident acuity given the range of need, and how to staff according to that need. At the same time, it will be important to assure that changes are not overly “urban-centric” and that they avoid the “us vs. them” mentality—whether that be regulators vs providers, families vs staff, residents without vs residents with dementia, or the media vs the entire AL industry. The imperative to reimagine AL is a societal one.

Despite some innovative and promising models of AL, there is general consensus that overall, the current model of AL has been taken as far as it can go. As a society, we are asking AL to be a product very different than its original roots. Today’s AL is not meeting the demands being placed upon it, and attending to the tensions described in this paper may result in better care and housing options. To do so requires a focus on quality, involvement of all stakeholders, and proponents willing to lead change (such as was witnessed in nursing homes through the Green House model). Other providers, states, and organizations that are already leading with innovation could be among the change makers the industry sorely needs.

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