

## Introduction to Assisted Living Literature Review

This latest draft of the Claude Pepper Center Assisted Living Literature Review and Policy Analysis Paper draws on far more sources of information (over 50) than were included in the 2006 version sent to the Work Group last summer. The additional information may be of value to Work Group members in preparation for meetings and in gaining a more informed perspective on the larger context in which our discussions about Assisted Living (AL) regulations are occurring. Some of the more salient findings that emerge from the review include the following:

- The values most associated with AL (autonomy, choice, privacy and home-like environment) are, in fact, extremely important to AL residents, and AL providers have, for the most part, done an adequate or better job of achieving these values. This does not mean that the provider community can assume that the task is done and what they have achieved cannot erode if sufficient effort is not maintained. In fact, threats to this achievement may be inherent in two other major findings from our review.

First, aging in place in AL is occurring and probably increasing as the number of more impaired persons living in AL continues to grow. Aging in place has been part of the AL mission for almost two decades and is an important aspect of achieving the vision for AL as a major part of the long-term care (LTC) system.

Second, a substantial percentage of residents who are remaining in Assisted Living Facilities (ALFs) as they experience increasing impairment (aging in place), are persons living with dementia, the most common form being Alzheimer's disease. The research literature indicates that AL has the capacity to accommodate this growing segment of the population and may be, for many, a more propitious place to age in place than their own homes or nursing homes.

This does not mean however, that AL should become a massive substitute for nursing home level of care for very seriously impaired (physically or cognitively) persons.

- Policymakers should be careful and avoid relying excessively on what Rosalie Kane has referred to as the over utilization of AL. As noted in several articles and reports reviewed for this paper the typical profile of long-term residents in AL compared to residents in nursing homes is still substantially different and should probably remain so. Regulatory (less restrictive placement/retention criteria) and funding (higher costs for increased staffing) changes designed to create a convergence of profiles would in all likelihood turn AL into a slightly less regulated and slightly, if at all, less expensive version of the nursing home model. This would undermine the very characteristics (more autonomy, privacy and choice) that have made AL such an attractive option in the long-term care continuum over the last 20 years. This would be an unfortunately ironic development given the current efforts in several states by the Nursing Home Pioneers and Green House movements to create smaller, less regimented, more home-like nursing home environments.

AL has gradually developed the capacity to serve a more impaired resident population but may now be approaching the threshold of resident impairment (functional and medical needs) that must be preserved in order to maintain its qualitatively distinct difference from living in a nursing home. This issue would remain even if ALFs were evenly available across geographical areas and equally willing to take the Medicaid rate for ALF residents. Neither of these conditions currently exists in most states.

Furthermore, the current regulatory framework for AL in Florida underwent a major change in 1990-1991 with the passage of legislation establishing the ECC License and has evolved since then to accommodate changing perceptions of the proper role of AL in the LTC system. The research literature and expert opinion largely support the perspective that Florida's ALF regulatory framework would have to undergo substantial modification to accommodate a qualitatively more impaired population that is more comparable to the typical nursing home resident.

The current ALF regulatory framework is allowing many older people and younger people with disabilities, who would have been in nursing homes 20 or even 10 years ago to live in ALFs without turning them into poorly resourced nursing homes. Any regulatory changes that might put this carefully constructed balancing act at risk should not be undertaken lightly.

- With the huge growth in the number of persons living with dementia in AL, the need to pay much closer attention to their service needs and quality of care and life has grown as well. More research focusing on these issues is showing up in the literature but far more is needed, especially research on the quality of life of residents with dementia. AL has clearly demonstrated its capacity to serve this population, but, as it grows, policymakers, providers and the public need to know more about what should be required in dementia specific units, what kinds and amounts of training should be provided to administrators and caregivers, what type of living arrangements and activities are best for residents as they progress through the stages of dementia and what might be needed in terms of regulatory changes to improve the quality of care and life for this population.
- AL has been a major source of housing and services for persons living with mental illness for several years in Florida and many other states, without a clear consensus emerging about what AL for this population should be expected to provide and be held accountable for beyond the requirements of the Limited Mental Health License. This lack of consensus includes the relationship between ALFs and the larger mental health provider community and the proper roles and responsibilities of each, the qualifications and training requirements for administrators and staff in ALFs with residents needing mental health services and many other important regulatory issues that have been debated for years without consensus being reached.

The absence of research findings related to these issues greatly hampers the ability of policymakers, advocates, providers and the public to obtain the breadth and depth of information needed to generate a consensus on what should be done and what it might cost. This does not mean, however, that efforts to more systematically address the housing and services needs of persons living with mental illness in the community should continue to be

delayed until more research information becomes available. Public officials, housing and mental health experts and advocates should conduct a collaborative initiative to develop a range of housing and services models including cost estimates, funding strategies and regulatory systems, for this population (based on the best available information).

- Cost, of course, is a major challenge for AL generally and for all the populations living in ALFs. Although the research literature has increased steadily over the last several years, AL cost studies are still rare and the few that have been done are far from adequate. As the need for more AL capacity increases with the growth of the 75+ population over the next three decades, and economic pressure continues to be felt in both the public and private sectors, policy makers, the public and private providers are going to need far more accurate information than what is currently available about AL costs and the financial impact of possible regulatory changes.

The monthly cost of AL for residents paying from private sources has been increasing by 5-10% annually for several years and now average about \$3,200 a month (\$38,000 annually). This rate of increase is unlikely to abate over the next several years as the demand for AL increases with the growth of the 75+ population. This trend is likely to put AL increasingly beyond the reach of those who need a residential alternative to their own home, but who do not require nursing home level care. This trend is also likely to perpetuate and possibly increase the current gap between the amount charged to private pay residents and what state and federal governments will pay for Medicaid supported residents or for residents supported by other public sources.

Resolving these discrepancies between the demand and need for AL and its affordability will be one of the nation's major long-term care challenges over the next several years and will keep the need to balance the relationship between cost and regulation permanently on the policy agenda along with the need to achieve greater efficiencies in service delivery and facility financing. Regularly conducted cost and outcome evaluation studies should help policymakers and providers identify potential efficiencies on a continuing basis.

These kinds of policy oriented analyses, however, will depend on the routine collection of resident characteristics and service cost data. This will require the development of resident and services information systems similar in design to those now administered by nursing homes, but requiring the collection of less data at less frequent intervals.

- In our view the AL research completed since the 2003 national AL Work Group is generally consistent with the findings from the pre-2003 literature in providing evidence supportive of the vast majority of regulatory recommendations made by the Work Group and addressed at length in this paper. The Work Group did not address every regulatory issue and others have arisen since they released their report. On the whole, however, the 2003 Work Group report still provides a solid framework for the formulation of regulatory models for AL and the identification of gaps.

It would probably be helpful to all affected parties to reconvene the Work Group in 2013 to review the 2003 report in terms of new knowledge and 10 years of experience across the states in the management of AL growth and change.