

Alzheimer friendly assisted living regulation

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Abstract

Assisted living is increasingly recognized as an important option for people with Alzheimer's and related disorders. Although 30 to 40 percent of people in assisted living and residential care settings are suffering from dementia, regulations in many states have not kept pace with this reality. This article identifies areas where regulations may support or undermine assisted living providers serving those with dementia, and suggests ways in which regulators, advocates, and providers may work together to create Alzheimer friendly assisted living regulation.

Background

Among residents of assisted living and other residen-

tial care settings, 30 to 40 percent suffer from Alzheimer's and related disorders. As the following table shows, this percentage has held constant in several studies. Such residences—their environment, operations and the regulations within which they operate—have not, up to now, generally been specially planned to meet the needs of this large group. As long term care systems in the United States evolve, and especially as states revise their residential care regulations to encourage more individual choice about how people arrange for the services they need, the opportunity presents itself to reconceptualize how cognitively impaired older people are best served in residential settings.

Laws and regulations governing residential care, a State function, vary considerably from state to state. Nationally, however, a shift is taking place from supportive housing seen as a step in people's continuum of

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Date	Source	Author/PI	Percent dementia
1995	Research Triangle/ASPE	Catherine Hawes <i>et. al.</i> ¹	35.7 percent of 3400 residents in 10 states were moderately to severely cognitively impaired
1995	UMass Medication Management Study	Joan Hyde ²	27 percent of original sample require family consent and participation due to cognitive impairment
1993	Coopers & Lybrand with ALFA	Al Holbrook ³	42 percent have some form of cognitive impairment
1993	AARP	Rosalie Kane, Keren Brown Wilson ⁴	65 percent of assisted living facilities surveyed reported serving people with cognitive impairment
1992	UCLA Andrus Center	Victor Regnier ⁵	40/40 rule: In international survey of assisted living at least 40 percent of residents cognitively impaired, 40 percent incontinent
1989	Harvard East Boston Study	Dennis Evans <i>et. al.</i> ⁶	47.2 percent over age 85 and 18.7% ages 75-84 among community living elders have diagnosable Alzheimer's disease

care, to assisted living seen as a resident's own home. "Board and care" and other variously named supportive housing facilities are declining in emphasis compared to an assisted living philosophy (regardless of the regulatory category and name given to it in various states), in which such residences now considered the resident's home, function as a platform for a wide range of services to be coordinated and delivered as needed.

This article compares best practices in Alzheimer's care to regulations and regulatory practices in a sample of ten states. The researchers used content analysis and interviews with regulators, providers, consumers and researchers to determine the degree to which regulations in those ten states supported the ability of providers to serve people with dementia in assisted living and residential care facilities. Based on these findings, draft model regulations were prepared and sent with a survey rating attachment to the original study informants as well as to attendees at a national Alzheimer's Association conference, and a conference for state health care regulators. Final model regulatory language was then proposed that is intended to be "Alzheimer friendly" and to ensure that people with cognitive impairment can receive the services they need in residential settings.

The range of general regulatory approaches in the 10 study states

In order to set a context for a discussion of the Alzheimer friendliness of regulations, it is important to understand the other ways in which residential care regulations vary. These include nomenclature, content areas covered, state philosophy regarding the nature of residential care, and the age of the regulations.

Residential/Resident Care Facilities/Homes	6
Personal Care Homes	3
Board(ing) Home/Lodging/Care Facilities	3
Assisted Living Facilities/Centers/Residences	3
Homes for the Aged	1
Rest Homes	1
Sheltered Care Homes	1
Domiciliary Care	1

Nomenclature

Regarding the names used to categorize residential care facilities, there is little consistency from state to state. Among the 19 different residential care categories found in the 10 study states, there were eight different names. Except for those codes that use the name Assisted Living which always means that the regulations are relatively new, one cannot tell anything about the characteristics of the regulations or the types of facilities so named simply by the nomenclature.

Content of regulations

The content of regulations are, if anything, even more diverse than nomenclature. While there is consistency in basic requirements, such as that the administrators of such residences be "18 years of age or older and of good character," regulations differ widely in other areas. Some states have very detailed physical plant requirements, while others address only life safety issues. A few states have dietary regulations that spell out detailed nutritional requirements and health standards, while others specify nothing more than the number of meals per day that the facility may serve. The level of specificity and the actual language regarding services, training, and staffing also vary widely. Formats, order of areas covered, even language regarding basic concepts are so different as to make comparisons difficult. Given that we are currently in the midst of a national debate regarding state control of key health and social services, the advantages and disadvantages of this diversity of content are instructive. In some ways this local control allows for regulations that address local conditions. For example, regulations in some Southern states specify that there must be screens on the windows and specify maximum interior temperatures, while regulations in Maine require that facilities must keep roads to the facility clear of snow for use by emergency vehicles. On the other hand, the diversity of regulations adds costs and difficulties for multi-state providers, and reduces the ability of providers to replicate successful models from state to state.

Philosophy

Compared to nursing homes, there is little consistency from state to state regarding goals and purposes in the residential care/assisted living area. In some states residential care is regulated as a supportive housing or social service provider, while in others it is viewed as mini nursing care setting and is then typically regulated by the same agency that regulates nursing homes. Table C shows

that there is little relationship between the medical/psychosocial orientation of regulations and the breadth of admission criteria.

The 10 states studied for this project were ranked as "medical" or "psychosocial" model by the researcher—based on the agency regulating, the quantity of regulatory language dedicated to nursing and health-related issues, and the opinions of study informants. The terms "narrow" and "broad" were used to describe the approach states have to the ability to serve a wide range of individuals, and the ability of such residents to "age in place" once they move to a residential facility. The primary basis for this aspect of the ranking was content analysis of the admissions and discharge criteria in the regulations, along with informant information. Thus, implicit in some regulations is the view that residential care is a step in the continuum, with a fairly narrow band of needs that may be served in such settings. Other states subscribe to a view that residential care facilities are settings where a wide range of residents' needs may be addressed.

While one might logically expect psychosocial orientation and broad admission policies to cluster in newer regulations, this is not the case. Psychosocial vs. medical orientation is not correlated to either the newness of the regulations nor the narrowness of admission and service capabilities of these settings. Some states that have instituted new assisted living regulations have restricted these residences to relatively independent elders, while others allow anything from meals and housekeeping to nursing care to be provided. Some states which allow a narrow range of impairment, even when this means limiting nursing care allowed, nonetheless have a nursing and medical orientation, as do some with a wide range of permitted impairments.

Updated regulations

States have one of three types of regulation—older traditional regulations; new "assisted living" regulations, and old regulations with revisions to bring them up to date. There was no relationship between the age of the regulations and either their medical orientation or their Alzheimer friendliness. Some newly-written assisted living regulations allow for a wide range of disabilities and the flexibility needed to serve people with dementia, while other new regulations treat assisted living as a setting for those who can manage their own services, and thus make it difficult to serve those who cannot. Some older regulations, written when social attitudes assumed that many old people were merely "senile" and in need of

Table C Correlation of range of impairment to orientation of regulations

		Range of impairment	
		Broad	Narrow
O R I E N T A T I O N	Psychosocial	Massachusetts Michigan Virginia	California New Jersey
	Medical	Florida Maryland Pennsylvania	Illinois Ohio

a supportive homelike setting, are basic, sensible, and surprisingly Alzheimer friendly. Others among the older regulations are detailed and proscriptive in ways that do not meet the needs of those with dementia.

Defining the Alzheimer friendliness of regulations

The remainder of this article focuses on the ways in which some regulatory language supports providers wishing to serve people with dementia, while other aspects of regulations may impair providers' ability to serve those with Alzheimer's disease. The conclusions presented here are based first on an analysis of the literature on best practices in dementia care, (AHMA, Alzheimer Association and Hearthstone) from which the researchers developed a systematic inventory of factors that are thought to be important to serving people with dementia in residential settings. This inventory was compared to a listing of the range of items commonly addressed in regulations.

Based on interviews with providers, consumers and consumer advocates, regulators and researchers, the team drafted model "Alzheimer friendly" language which addressed all aspects of regulations in which states are likely to be interested. These draft regulations were then distributed to an even larger group of providers, consumers, consumer advocates, regulators and researchers, and the final model regulations were modified to address their rankings and comments.² The left column of Table D provides an overview of the systematic inventory of best practice areas that may be addressed in regulations, while the data in Table D reflect state rankings in terms of Alzheimer friendliness.

Table D1 Analysis of assisted living/residential care regulations

Area of regulation	Alzheimer friendly	Silent/neutral	Counter to best Alz. practices	Total
I. Administrative issues				
A. State assisted living mission and philosophy				
1. Definition of assisted living	4	5	3	12
2. Contract and services based on individual service plan	4	4	2	10
3a. General facility disclosure requirements	1	9		10
3b. Disclosure requirements for Dementia Special Care Units		10		10
B. Licensure, registration, or certification				
1. Licensure, registration, or certification	3	4	3	10
2. Regulator and surveyor training		7	3	10
C. Waivers and flexibility				
1. Waivers and demonstration projects	3	6	1	10
2. Establishment of an advisory group	3	2	5	10
3. Participation on state advisory panel	2	3	5	10
D. Local zoning and building code approvals		7	3	10
E. Financial support for low income residents			10	10

Key areas in which regulations may effect the Alzheimer capability of residential care

The following are the areas of the regulations that the study informants found to be most significant to the ability of providers to serve people with dementia. The study found major differences between states in the degree to which regulations reflect an understanding of the large percentage of assisted living residents who suffer from cognitive impairment. Admission and discharge criteria, allowable services, and operational requirements vary greatly in the extent to which they address the needs of the Alzheimer population. Key areas in which state regulations support or create obstacles to best practices in dementia care include the topics discussed below.

Admission and discharge

Overall, the most serious regulatory obstacle to serving people with dementia are restrictive admission and discharge criteria. More than half of the states studied had admission and discharge criteria that restricted admission and sometimes retention of people with cognitive impairment, behavior problems, and some of the symptoms common to dementia such as incontinence. These restrictions tend to be underenforced, but nonetheless have a chilling effect on residences' ability to serve this population.

Role of the family

Along with restrictions on admission and discharge, there tends to be lack of recognition of the family's role in resident decision making. In more Alzheimer friendly states, regulations describing such issues as resident rights to participate in their service plan include statements such as "the resident or representative," or even "the resident and or family member." In other states the family has no such standing unless legally designated as guardian.

Building requirements

Design and life safety issues are the next most serious area of obstacles to serving people with dementia. States that require full nursing home type building standards when the provider serves those who cannot evacuate independently, effectively change the admission and discharge criteria to prohibit cognitively impaired residents. While many providers wish to build residences with safety features such as non-combustible building materials, sprinklers, and other fire safety features, the interpretation among design reviewers of the "I-2" classification in most states for nursing homes includes other features that can make a building less residential. "Nurses' stations, eight-foot corridors and handrails typically become part of the 'I-2 package,' even though they have little to do with life safety."⁵

Table D2 Analysis of assisted living/residential care regulations

Area of regulation	Alzheimer friendly	Silent/neutral	Counter to best Alz. practices	Total
II. Operational program model factors				
A. Resident characteristics				
1. Admission and transfer criteria	4	2	6	12
2. Resident rights, risk, and autonomy	1	6	3	10
3. Role of the family or other legal representative	3	4	3	10
B. Assessment and service planning				
1. Interdisciplinary team approach	1	5	4	10
2. Assessment and service plan schedule		10		10
3. Regulatory review		9	1	10
C. Services				
1. Personal care	8	2		10
2. Service coordination	3	7		10
3. Medication management	8	2		10
4. Dietary services	3	3	4	10
5. Medical coordination and nursing care	6	4		10
D. Staffing				
1a. Staff ratios and patterns (general)	9		1	10
1b. Staff ratios and patterns (Special Care Units)	1	9		10
2. Training, qualifications, and interdisciplinary team	4	5	2	11
E. Activities				
1. Duration, suitability, and inclusion of ADLs and IADLs in activities programming	5	6	1	12

Exit control

While exit control that is both immediate and unobtrusive is key to providing quality dementia service, at the time of the study four states prevented or severely limited residences from instituting effective exit control strategies. Strategies and mechanisms for exit control include "reverse" fire-doors with delays that open when there is a fire, but are locked magnetically the rest of the time, coded push pads to override such a system, and various warning devices such as buzzers or lights. Facilities have considerable difficulty providing quality services in those states that forbid exit control mechanisms. A number of residences in those states report that they use exit controls they feel are safe and necessary despite the regulations.

Kitchens, bathrooms, and square footage in individual units

Some of the newer regulations in states that envision assisted living serving a less impaired population, require

full apartments, with larger square footage requirements, kitchens and full bathrooms. The added cost, size and complexity of such spaces make them impractical for serving a cognitively impaired population.

Financial support

Lack of adequate support for lower income elders was another key problem. While some states have limited support through social security supplements and occasionally through Medicaid community-based waiver programs, these programs do not provide enough funding to cover the amount of staff time needed by this population.

Model of care

Another area of regulation that leads to difficulties in serving those with dementia is a heavy emphasis on a medical model of care. This orientation is evident in the staffing requirements, and even more in the assessment and service planning area. Some states require nurses and

Table D3 Analysis of assisted living/residential care regulations

Area of regulation	Alzheimer friendly	Silent/neutral	Counter to best Alz. practices	Total
III. The physical environment and life safety				
A. Exit control and wandering paths	3	3	4	10
B. Private spaces				
1. Single and double occupancy of private spaces	7	2	1	10
2. Locking of living units	3	7		10
C. Kitchens and bathrooms	4	5	1	10
D. Common areas	5	5		10
E. Access to out-of-doors				
F. Building codes and life safety				

sometimes even doctors to oversee the care plan and the required information and planning is exclusively medical in nature. While these regulations do not preclude family members, resident assistants or social workers from participating in the service plan process, the regulatory requirements tend to undermine their contribution. These states also tend to have a survey process that emphasizes the nursing aspects of care, skewing the orientation of the provider toward this area, and potentially taking resources away from activities and other services important for cognitively impaired residents.

Dietary requirements

More minor, but troublesome issues were found in states with extremely detailed dietary requirements. For example, one state's regulations require that "any vegetable or fruit repeated for the day shall not be counted as one of the four servings required in this group." This requirement makes it difficult to serve a person with Alzheimer's who might have a few strong food preferences.

Activities

While a few states require an activities program, most did not recognize the need for an activities program at all. Only a few state regulations recognize the special activities needs of those with dementia. A few state regulations restricted residents from participating in such activity areas as meal preparation and laundry that are known to benefit the Alzheimer's population.

Medication management

On the positive side, all the states studied for this project allowed some form of medication management

that was at least moderately applicable and sometimes very appropriate for cognitively impaired residents. In the area of personal care and nursing services, most allowed an adequate range of services.

Regulatory and surveyor attitudes

Overall, survey informants reported that the literal content of the regulations had less impact on their ability to serve cognitively impaired residents than the attitudes, training and orientation of state regulators and surveyors. States with commissions or an advisory board that deal with dementia issues, or that include members of the Alzheimer's Association, even if the boards are not designated to address assisted living residences directly, tend to be more Alzheimer friendly in practice, even if the regulations, strictly read, are not supportive of serving this population.

Local building inspectors and fire marshals in most states have jurisdiction, leading to variation, not just from state to state, but often from town to town. For example, while state regulations may not prohibit exit control systems or require an I-2 building, a local fire marshal or building inspector may require it.

Analysis of Alzheimer friendliness of regulations in a sample of 10 states

Table D uses the systematic inventory of factors described above to help us understand how states may differ in their approaches to Alzheimer's in their residential care regulation.

A regulatory element was deemed to be "Alzheimer friendly" if it specifically fostered best dementia care

Table E State by state Alzheimer friendliness

State	Alzheimer friendly	Counter to best Alz. practices	Silent/Neutral	Total
California	12	6	15	33
Florida	8	8	17	33
Illinois	6	10	18	34
Maryland	8	7	19	34
Massachusetts	14	1	18	33
Michigan	5	10	18	33
New Jersey	13	11	12	36
Ohio	13	5	15	33
Pennsylvania	13	8	14	35
Virginia	11	7	16	34
Total	103	73	162	338
Average	10.3	7.3	16.2	

practices regarding that issue. It was deemed to be "Counter to best Alzheimer practice" if it prevented such good practice, and "Silent/neutral" if it would allow, but did not foster best practice. For example, in the area of Interdisciplinary Team Approach in Assessment and Service Planning (II.B. 1) a regulation that prescribes that a nurse or physician must take total responsibility for assessment and service planning, is considered counter to best practices, while one that mandates the inclusion of families, social service, direct care and activities personnel is considered Alzheimer friendly. Regulations that require an assessment and service plan, but do not specify who is to perform that function or what it is to include, or one that does not require a plan at all, was scored as "Silent/neutral." This table and the previous one allow multiple scoring within a given content area when some aspects are Alzheimer friendly and others are not. Therefore, the total number of responses to the 33 areas in 10 states equals 338.

Most states were silent or neutral in at least half of the content areas, with a range from Maryland, which has fairly general language, to New Jersey which has lengthy new regulations that address many issues in considerable detail. Where regulatory elements are applicable to Alzheimer's friendliness, more are positive (103 of 176, or 58.5 percent) then counter (73 of 176, or 41.5 percent), but in nearly half of all possibilities (162 of 338, or 47.9

percent) the regulations are silent.

Further analysis of this table yields an understanding of those areas of regulation that are most likely to be problematic for dementia populations. The one area in which all states were deficient is financial support for low-income residents. While nursing homes may slightly underreimburse for this population, social security payments and occasional Medicaid waiver programs that are available for residential care support are typically marginally adequate to cover the room and board costs of frail elders who require few services, and are totally inadequate to cover the costs of 24-hour supervision and assistance with activities of daily living that are needed by many people with dementia living in these settings. This item in the table, along with lack in many states of advisory boards with Alzheimer expertise to support flexibility, made the Administrative area the least Alzheimer friendly overall.

The other area that was overwhelmingly counter to Alzheimer best practices were the building codes. These either were very nursing home like, or they were based on a housing code, in which case they precluded residency by people who cannot self-evacuate, such as those with dementia.

Table E summarizes the distribution of Alzheimer friendly elements across the states selected. This chart is of interest to those who are using or providing assisted living for people with dementia in the 10 states listed.

Table F Correlation of Alzheimer friendliness to orientation

	Broad	Narrow
Psychosocial	4.0	3.5
Medical	2.0	2.0

Further analysis yields several general conclusions which may help states as they write or amend regulations.

We may analyze the overall effect of the regulations by subtracting the average "Counter to Best Alzheimer Practices" score, from the average "Alzheimer Friendly" score. Averaging these state scores by category from Table C yields Table F, in which we find that the regulations in those states which have a psychosocial orientation are more Alzheimer friendly than those in the medical model states. This holds regardless of whether the regulations allow for a narrow or broad interpretation of residential care, with those states that are both broad in their admission and discharge criteria and psychosocial in their orientation, being the most Alzheimer friendly.

In sum, advocates and regulators would do well to recognize the extent to which residential care and assisted living residences presently serve people with Alzheimer's disease, and work to modify their regulations accordingly. The basic principles that have been found to be important to quality care and quality of life include:

- Admission and discharge criteria that allow for aging in place and for the common symptoms of dementia;
- Support for, and an ongoing relationship with families;
- Building codes that are realistic for people who need guidance during emergencies and that allow for safe exit control;
- Individual or shared bedrooms of a manageable size and complexity that allow personalization, and do not require individual kitchens; and
- Emphasis on a psychosocial model of care that respects the individual resident with all his or her history and current strengths and deficits.

Regulations need to foster services, including activities, medications management, food and personal care that meets the specific needs of those with Alzheimer's and related disorders. Finally, no matter how Alzheimer friendly regulations are, this is an evolving field. All states that want to remain current will need an advisory or

review board that includes representatives of the local Alzheimer's Association or other dementia experts, who would consider requests for special demonstration projects or waivers.

Providers who seek to offer the best in dementia care in assisted living settings, are advised to take the time to establish relationships with regulators. In this way they can explore with them how best to apply existing regulations, and change regulations when necessary to foster Alzheimer friendly assisted living.

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