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Re: Regulation 14514 (Assisted Living Residences)

Following the 2007 investigative series in *The Philadelphia Inquirer*[1] demonstrating the inadequate oversight of assisted living facilities in Pennsylvania, the Legislature passed Act 2007-56 to require better oversight of the assisted living industry. Unfortunately, the regulations proposed by the Department of Public Welfare fail to implement the law in a way that protects Pennsylvania's assisted living residents. Instead, the proposed regulations generally perpetuate the inadequate standards and oversight for the board and care industry, while allowing these same facilities to use the name assisted living.

[1] The four major articles in *The Philadelphia Inquirer* series were: "Shame of the State; Troubled facilities and lax state oversight have for years put residents of Pennsylvania's assisted-living homes at risk of assault, neglect – and tragedy" (Feb. 25, 2007); "Criminal neglect, overlooked cruelty: Rotten food, violence and suspicious deaths – and state regulators fail to see it" (Feb. 26, 2007); "Writing their own rules: Drive for change left Pa.'s personal-care industry at the wheel" (Feb. 27, 2007); and "A dysfunctional system: A jumble of state-by-state rules let a chain of horrors grow" (Feb. 28, 2007).

The Center for Medicare Advocacy (the Center) is a non-profit organization that provides education, analytical research, advocacy, and legal assistance to help older people and people with disabilities obtain necessary health care. The Center focuses on the needs of Medicare beneficiaries, people with chronic conditions, and those in need of long-term care. The Center urges the Department of Public Welfare to rewrite the proposed regulations and to establish standards of care and an oversight structure that will ensure that residents receive the care and services they need.

The Center supports and endorses the comments of the Pennsylvania Assisted Living Consumer Alliance and submits the following additional comments:

The proposed standards of care are inadequate

The proposed regulations do not implement the best current thinking about assisted living and how to regulate this industry. They create a single level of care in assisted living, perpetuate inadequate staffing standards, do not clearly identify which services an assisted living residence must provide, fail to include necessary protections and rights for residents, and allow board and care facilities to rename themselves as assisted living while not meeting assisted living standards (perpetual grandfathering).

Levels of care

The proposed regulations create a single level of care that covers all assisted living residences (ALRs), regardless of the care needs of their residents. ALRs may serve residents with vastly different needs. Residents who do not have cognitive impairments, for example, may have very different needs from residents who are placed under a Medicaid waiver and, by definition, need a nursing home level of care. The Center contends that one set of regulations covering all types of ALRs does not serve residents well.

Recommendation: Pennsylvania should establish several levels of assisted living and adjust some of the requirements (e.g., staffing) to the needs of the residents in each level. ALRs must meet additional service and care requirements if they serve residents with dementia.

Staffing (§§2800.51-.69)

Staffing is the critical component of any residential setting for people who have health and care needs. The proposed regulations do not assure that ALRs have sufficient numbers of direct care staff or that direct care staff are appropriately qualified and trained to meet the needs of their residents.

The distinction between "mobile" residents and residents with mobility needs (§2800.57) is one distinction that can be made among residents, but it is not the only distinction that matters for purposes of appropriate staffing. §2800.65(a) allows direct care staff to be trained in fundamental fire safety and other emergency procedures for the first time when they report to work, a grossly inadequate standard; §2800.65(d) says that direct care staff must successfully complete and pass a Department-approved training course, but the course is not discussed elsewhere in the regulations. §2800.65(b) allows only "orientation" of new staff within 40 working hours, not pre-employment

training and competency, in a variety of issues, including residents' rights and emergency plans. The proposed regulations allow "volunteers" to provide direct care services to residents, but contain no limitations on the type and quantity of care and services that volunteers can provide (§2800.4).

Recommendation: Require an adequate number of direct care staff to meet residents' needs. Require a sufficient number of direct care staff on-site 24 hours per day in all ALRs. Establish separate staffing ratios for different levels of care, including Special Care Units (§2800.231-.239).

Recommendation: Establish training requirements for direct care staff, including curriculum, and set out a process to ensure that the Commonwealth determines that direct care staff are competent before they provide care and services to residents.

Recommendation: The regulations must require more than an "on call" nurse, which the regulations do not define. Depending on the needs of the residents, nurses must be available on-site.

Recommendation: Establish staffing requirements for social services, activities, housekeeping, and administration that are appropriate to the level of assisted living care that the ALR provides. Strengthen the educational and training requirements for administrators.

Recommendation: Delete the provision allowing volunteers to provide direct care services to residents.

Recommendation: Require that Special Care Units for residents with dementia have additional staff who are specifically trained in how to care for individuals with dementia.

Admissions (§2800.22)

The proposed regulations allow ALRs to give certain information, including assessments, support plans, and contracts, *after* admission. The Center contends that "after admission" may be too late. ALRs must give information to potential residents *before* admission so that they can decide if the ALR will be a good fit. ALRs must complete assessments before admission to ensure that they will be able to meet a potential resident's needs.

Recommendation: Require ALRs, before admission, to give residents full, complete, and accurate information about services, charges, and ALR policies.

Recommendation: Require ALRs to complete resident assessments before admission, not 30 days after admission (§2800.22(4)), so that the ALR and the resident and family can have reason to expect that the placement is appropriate and will serve the resident's needs.

Contracts (§2800.25)

ALRs must give residents contracts before or at the time of admission, not later. The proposed regulations identify "admissions fees," but say nothing about them (§2800.25(c)(6)).

Recommendation: Require ALRs to give residents at least 60 days' advance notice before raising rates.

Recommendation: Require ALRs to waive the requirement that residents give 14 days' advance notice that they will leave when their residency ends with death.

Recommendation: Prohibit ALRs from charging admissions fees to residents.

Recommendation: Prohibit contracts from waiving any statutory or common law rights of residents and from including waivers of liability.

Informed consent process (§2800.30)

The section on informed consent appears to be a new term for the discredited term "negotiated risk." The Center opposes negotiated risk or informed consent contracts. As described in §2800.30, the informed consent process allows an ALR to require a resident to sign an informed consent process or face eviction from the facility (§2800.30(f), (g)).

Recommendation: Delete §2800.30 in its entirety.

Residents' rights (§2800.42)

Many rights that are guaranteed to residents in other residential care settings, such as nursing homes, have not been included in the proposed regulations. The right to have visitors (§2800.42(r)) is exceptionally limited.

Recommendation: The regulations should add rights

- to have 24 hour, seven days per week access to family and friends;
- not to be transferred or discharged except for specified reasons (ALR's inability to meet the resident's needs, even with reasonable accommodations; non-payment; closure of the ALR). Residents who spend down their income and are eligible for Medicaid must be allowed to remain when the ALR has a Medicaid waiver bed available;
- to equal treatment, care, and services, regardless of source of payment;
- to prohibit supplementation for residents under a Medicaid waiver (the Medicaid rate is payment in full for covered services);
- to choose one's own health care providers, including physician and pharmacy (Delete the language in §2800.142 that allows ALRs to require residents "to use providers of supplemental health care services approved or designated by the residence.")

Financial management (§2800.20)

The proposed regulations do not address a number of specific protections for financial matters.

Recommendation: Prohibit ALRs from requesting or requiring the right to be, or from being, representative payee for residents.

Recommendation: Prohibit ALRs from requiring residents to give them authority to handle the residents' funds.

Recommendation: Prohibit ALRs from charging residents for handling residents' funds.

Recommendation: Require that ALRs give residents, or their estates, a full and complete accounting of any funds handled by the ALR within 30 days of a resident's transfer, discharge, or death.

Medications (§2800.181-.191)

The proposed regulations do not define self-administration or medication administration. They do not identify which staff members may help residents with self-administration of medications and which staff members may administer medications.

Recommendation: Define self-administration of medications and medication administration.

Recommendation: Confirm that staff may assist with self-administration of medications and may administer medications, only as authorized by Pennsylvania's nurse delegation act for health care providers.[2]

Physical site (§2800.81-.109)

The proposed regulations create one set of size requirements for new construction and another set for facilities that convert to ALRs (§2800.101(b)(1), (2)). They also create one set of kitchen requirements for new construction and another set for facilities that convert to ALRs (§2800.101(d)(1), (2)). The Center opposes these provisions, which allow existing facilities to become ALRs without meeting the requirements for ALRs, effectively grandfathering them in forever. The size requirements for residents' units are too small. There needs to be sufficient space for residents to bring in and use personal furniture and objects.

Recommendation: Prohibit grandfathering for size and kitchen requirements for facilities that are converting into ALRs. If facilities cannot meet ALR requirements, they should not be allowed to identify themselves as ALRs; they should be licensed, instead, under the appropriate licensure

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[2] As of June 2003, the law did not allow delegation. Rutgers Center for State Health Policy, *Nurse Delegation of Medication Administration for Elders in Assisted Living* (June 2003), http://www.cshp.rutgers.edu/PDF/Nurse%20Delegation%20of%20Med%20Admin%20for%20Elders%20in%20AL.pdf

category whose standards they meet.

Recommendation: Ceiling height must be at least 8 feet (not the 7 feet in the proposed regulations, §2800.101(e)).

Recommendation: Prohibit firearms and weapons (§2800.108).

Services (§2800.220-.229)

The proposed regulations do not define the core services that all ALRs must provide. Without a clear definition of these services, the term ALR remains undefined and confusing to consumers who are choosing an ALR and monitoring care and services.

Recommendation: Define core services to include social services by a licensed social worker.

Recommendation: Define supplemental services that ALRs may provide.

The proposed enforcement provisions are insufficient

The proposed regulations establish three classes of violations, depending on the severity of the deficiency (§2800.261). Daily penalties are available for the two most serious categories of deficiencies, but not for the third category. Daily penalties are $20 per resident per day for class I deficiencies, which are defined as having "a substantial probability of resulting in death or serious mental or physical harm to a resident;" $5 per resident per day, with a maximum of $15 per resident per day, for class, for class II deficiencies that have "a substantial adverse effect upon the health, safety or well-being of a resident." No penalty is available at all for class III violations, which are defined as "minor violations, which have an adverse effect upon the health, safety or well-being of a resident." Facilities must place $500 in the state's escrow account in order to appeal the fines (§2800.263).

The Department may temporarily revoke an ALR's license, but only for not correcting violations within specific time periods (§2800.266). The Department must ban admissions under certain circumstances (§2800.269).

This enforcement scheme is too limited. Enforcement is imposed essentially for failure to correct deficiencies, not for the existence of deficiencies. The civil penalties are too small to have any deterrent effect; penalties must be larger than the cost of compliance to be effective.

Recommendation: Establish an effective monitoring protocol that includes unannounced and unpredictable annual surveys and complaint investigations.

Recommendation: Increase the amount of penalties for all classes of violations and authorize penalties for class III violations.

Recommendation: Authorize the Department to impose penalties when it first identifies and

cites a deficiency; the Department should impose larger penalties for deficiencies that are uncorrected or repeated.

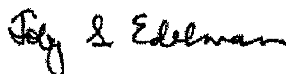
Recommendation: Expand the types of available remedies to include monitors, directed plans of correction, temporary management, and receivership.

Recommendation: Require the Department to establish a protocol for choosing which remedies to impose in particular situations. Enforcement is more likely to occur and is more likely to be effective and consistent when the Department uses an enforcement protocol.

I am enclosing a copy of *Policy Principles for Assisted Living* (April 2003), which was developed by regulatory agencies and consumer groups in 2003 and proposes a framework for regulation of assisted living.

Thank you for the opportunity to comment on the proposed regulations.

Sincerely,



Toby S. Edelman
Senior Policy Attorney

Policy Principles *for* Assisted Living

April 2003

- Association of Health Facility Survey Agencies
- Center for Medicare Advocacy
- National Association for Regulatory Administration
- National Association of Local Long Term Care Ombudsmen
- National Association of State Ombudsman Programs
- National Citizens' Coalition for Nursing Home Reform
- National Committee to Preserve Social Security and Medicare
- National Network of Career Nursing Assistants
- National Senior Citizens Law Center

Table of Contents

Acknowledgments and Contact Information 2

Executive Summary 3

I. Assisted Living Standards Must Be Strengthened 4
   A. "Assisted Living" Is an Expansion of a Longstanding Residential Care Model
   B. Problems Are Mounting In Assisted Living

II. "Assisted Living" Must Be Defined In a Meaningful Way, and Governed By Standards That Guarantee a Reasonable Level of Quality 6
   A. Standards Are Needed To Assure an Adequate Quality of Care
   B. The Setting of Standards Should Not Be Left to a Facility's Contract

III. States Should Establish More than One Level of Assisted Living Licensure 8
   A. "One-Size-Fits-All" Does Not Fit Well
   B. Level-of-Service Licensing Enables Consumers to Make Meaningful Comparisons, and Facilitates Establishment of Appropriate Standards

IV. Assisted Living Facilities Should Be Subject To the Same Non-Discrimination Rules that Govern Nursing Homes, to Assure That Low-Income Medicaid Beneficiaries Are Treated Fairly 10
   A. The Medicaid Program Covers an Increasing Number of Assisted Living Residents
   B. Facilities Voluntarily Accepting Medicaid Payments Must Comply With Medicaid Requirements
   C. Medicaid-Participating Facilities Should Be Required To Accept Medicaid From Residents Who Become Financially Eligible For Medicaid While Residing At the Facility
   D. Medicaid-Participating Facilities Should Be Required To Accept Medicaid As Payment in Full for Covered Services

V. The Federal Government Should Take an Active Role In Assuring that Assisted Living Residents Receive Quality Care 11
   A. A U.S. Senate Committee Has Recognized the Need to Protect Assisted Living Residents
   B. Existing Law Establishes Federal Jurisdiction Over Important Aspects of Assisted Living
   C. The Federal Government Should Exercise its Authority to Ensure the Quality of Assisted Living Services Funded Through Medicaid Waivers

VI. Conclusion 12

Acknowledgements

Thank you to the members of the participating organizations for generously donating their time in the development and preparation of this report. Thanks also to the American Bar Association's Commission on Law and Aging for making available the considerable expertise of its staff for consultation.

We are especially grateful for the leadership of the Senate Special Committee on Aging Chairmen – Senator Charles Grassley, Senator John Breaux, and Senator Larry Craig – for recognizing and working to address the existing problems in assisted living.

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Executive Summary

Although the assisted living model can have a vital place among available long-term care services, it will fail if it is allowed or expected to be all things to all people. The vulnerable residents of assisted living facilities deserve regulatory standards that define assisted living in an understandable way, and ensure an adequate quality of care.

Assisted Living Standards Must Be Strengthened. Recent newspaper stories illustrate the substandard care that too frequently is observed in assisted living facilities. Serious problems often are caused by a dangerous combination – vulnerable physically or mentally disabled residents with significant health care problems, cared for by a staff with minimal knowledge. The management and staff of assisted living facilities often do not have adequate experience or expertise in providing health care, even for relatively routine health care such as the management and administration of medication.

"Assisted Living" Must Be Defined In a Meaningful Way, and Governed By Standards That Guarantee a Reasonable Level of Quality. Standards should address the types of care provided, staffing levels, staff training, fire standards, and other important issues. The setting of standards should not be left to a facility's admission contract. It is unreasonable to expect an elderly individual in need of long-term care to negotiate the standards that the facility will follow.

States Should Establish More than One Level of Assisted Living Licensure. While a single one-size-fits-all standard may be appropriate for a facility whose residents have minimal needs, a single standard is inadequate to protect the increasing number of residents with significant health or mental health care needs. Far from protecting the most vulnerable, a "one-size-fits-all" system reduces standards to the lowest common denominator. A more effective system is to license assisted living at more than one level, with levels defined by the type and severity of the physical and mental conditions of residents that the assisted living facility is prepared to accommodate. Such a system is used successfully by a significant number of states.

Assisted Living Facilities Should Be Subject To the Same Non-Discrimination Rules that Govern Nursing Homes, to Assure That Low-Income Medicaid Beneficiaries Are Treated Fairly. Too commonly the assisted living industry wants the benefits but not the responsibilities of Medicaid reimbursement. Medicaid-participating facilities should be required to accept Medicaid from residents who become financially eligible for Medicaid while residing at the facility. Also, Medicaid-participating facilities should be required to accept Medicaid as payment in full for covered services, and should be prohibited from soliciting supplemental payments from residents' family members and friends.

The Federal Government Should Take an Active Role In Assuring that Assisted Living Residents Receive Quality Care. The federal government has jurisdiction over numerous important aspects of assisted living, and federal funding is responsible for a significant percentage of assisted living care. In addition, of course, the health and safety of vulnerable assisted living residents is a pressing concern. All of these are compelling reasons for an active federal role in assisted living. It is particularly appropriate that the federal government review the adequacy of state regulation when evaluating a state's application for a Medicaid waiver, given that waiver reimbursement is reserved only for those Medicaid beneficiaries whose medical needs are severe enough to warrant nursing home care.

I. Assisted Living Standards Must Be Strengthened.

Assisted living has much promise and, for some residents, provides a beneficial combination of housing and services. For too many residents, however, assisted living services are inadequate or substandard. We believe that consumers deserve better. Assisted living standards must be raised, and those raised standards must be enforced in a meaningful way.

A. "Assisted Living" Is an Expansion of a Longstanding Residential Care Model.

While the term "assisted living" first appeared fairly recently, the term describes a business that is not necessarily new. At its core, "assisted living" refers to services provided in conjunction with housing, for persons who cannot live independently.

In some states, "assisted living" is a new name for a pre-existing licensure category. In some cases the name change is made formally – in 2002, for example, Colorado renamed its "personal care boarding homes" as "assisted living residences."[1] In other cases the official name is unchanged, but "assisted living" has become the informal designation. California, for example, has licensed residential care facilities for the elderly since 1985, and it is those residential care facilities for the elderly that now are referred to commonly as "assisted living," even though the relevant law still refers to residential care facilities for the elderly.[2]

There are currently more than a dozen different designations for facilities that could be considered "assisted living," with more than one such designation in some states. For example, New Mexico licenses adult residential care facilities, and operates a Medicaid payment program known as assisted living.[3] Michigan licenses adult foster care facilities and homes for the aged, and also sets out requirements for contracts used by "housing-with-services establishments."[4] New York licenses adult homes, enriched housing programs, and assisted living programs.[5]

For years, residential care/assisted living was understood as a level of care falling between independent living and nursing home care. Appropriate consumers of an assisted living facility were those residents who required some assistance with activities of daily living, but did not have extensive medical problems. The very name "assisted living" suggests that such non-medical assistance was the principal service provided when the term "assisted living" moved into circulation in the early 1990s.

Assisted living has moved beyond its initial identity as a housing option for relatively healthy older people. The assisted living industry increasingly provides health care services, and it provides these services to a population that each year is becoming frailer, more dependent, and more similar to nursing home residents. Some chains and independent operators now contend that they should be allowed to compete directly with nursing homes, especially for the business of private pay residents.

B. Problems Are Mounting In Assisted Living.

Significant care and safety problems are not uncommon in assisted living. Furthermore, because assisted living facilities have less professional staff and fewer regulatory requirements than do nursing homes, and are less closely monitored by the states, it is likely that serious problems are more numerous than is currently known.

Recent news articles illustrate some of the problems. For example, one newspaper investigation of 25 local assisted living facilities found "[s]ubstantiated neglect and abuse cases . . . includ[ing] an outbreak of a highly contagious skin disease that went unchecked for months; a woman who was attacked in her bed by another resident; a man whose toe had to be amputated because of neglect; residents left injured and bleeding on the floors of their rooms; and a senile resident who wandered away unnoticed, collapsed and had to be hospitalized."[6]

In North Carolina, three residents from an assisted living facility were hospitalized within seven hours, each as a result of dangerously low blood sugar. The newspaper report noted that the low blood sugar could have been caused by inadequate food or improper doses of medication.[7] In Florida, "[m]ore than 25 residents were removed from an assisted living facility after state inspectors found them living with filth, insects and spoiled food, among other hazards."[8] In another incident from Florida, an owner and administrator of an assisted living facility was charged with criminal abuse or neglect in a death possibly caused by overmedication of an 88 year-old resident.[9]

Sources:

[1] *See* Colo. Rev. Stat. Ann. § 25-27-101.

[2] *See* Cal. Health & Safety Code § 1569.1 (residential care facilities for the elderly); Robert L. Mollica, National Academy for State Health Policy, State Assisted Living Policy 178 (2002) (identifying residential care facilities for the elderly as California's assisted living facilities).

[3] N.M. Admin. Code tit. 7, § 8.2.2; Robert L. Mollica, National Academy for State Health Policy, State Assisted Living Policy 328-332 (2002).

[4] Mich. Comp. Laws Ann. §§ 333.20101(3) (homes for the aged), 333.26502- 333.26504 (housing-with-services establishments), 400.703(4) (adult foster care facilities).

[5] N.Y. Comp. Codes R. & Regs. tit. 18, § 485.2 (definitions).

[6] Donna Callea, *Assisted Suffering*, Daytona Beach News-Journal, March 10, 2003.

[7] Nichole Monroe Bell, *Assisted Living Center Under Investigation*, Charlotte Observer, April 1, 2003, available at <www.charlotte.com/mld/observer/news/local/5529403.htm>.

[8] Jay Stapleton, *"Nasty" Conditions Prompt Removal of Assisted Living Residents*, Daytona Beach News-Journal, March 15, 2003, *available at* <www.news-journalonline.com/NewsJournalOnline/News/Local/areaN3031503.htm>.

[9] Kathy Ciotola, *Owner of Keystone Heights Nursing Home Charged in Patient's Death*, Gainesville Sun & Associated Press Newswires, November 3, 2002. Although the headline refers to a "nursing home," the text of the article identifies the facility as an assisted living facility.

Serious problems often are caused by a dangerous combination – vulnerable elderly residents with significant health care problems, cared for by a staff with minimal knowledge. For example, many assisted living facility residents suffer from significant and progressive dementia,[10] involving memory loss, altered awareness, diminished judgment or decision-making capacity, and difficulty with articulating needs. When individuals with significant dementia reside in a congregate assisted living setting with inadequate staffing and supervision, there is a constant risk of neglect, serious injury or adverse medical consequences from, among other things, falls, malnutrition, weight loss, wandering from the facility, resident-on-resident physical and sexual abuse, staff-on-resident abuse, and medication errors.[11]

The average assisted living resident is more than 80 years old and needs assistance to take medication or accomplish certain basic activities of daily living.[12] Because of advanced age, many residents have several chronic ailments and take a number of medications. They are likely to be susceptible to infections, dehydration, loss of appetite, and depression, all of which can lead to system imbalances. They can rapidly develop life-threatening conditions that require prompt recognition and treatment by medical professionals.

Risk factors can be reasonably controlled if a facility operator both understands the need to address these risk factors, and commits the resources to doing so. A facility must have competent professional nurse involvement in resident care, and appropriate numbers of well-trained and supervised personal assistance staff. But reports from around the country indicate that assisted living facilities often do not anticipate or respond to these risk factors as they should.

The problems facing the assisted living industry, and those trying to safeguard the interests of assisted living consumers, are serious and complex. Among the factors that make solving these problems difficult are the following:

- The management and staff of assisted living facilities often do not have adequate experience or expertise in providing health care, even for relatively routine health care such as the management and administration of medication.
- Assisted living facilities tend to rely excessively on minimally supervised direct care workers who, in the absence of professional nursing guidance, are inadequately prepared to assess residents' health status and care needs, or to perform complex tasks of care.
- Residents are sicker and require more care, as compared to assisted living residents five or ten years ago. The increased acuity level is the result of, among other things, shortened hospital stays, and in-home care options and health care technologies that delay long-term care entry.
- Assisted living facilities increasingly are used as residences for individuals with mental illness or developmental disability, but without recognition of those individuals' particular needs, and without adequate social service or mental health support.
- There is a need to more closely monitor health status changes and incidents involving residents, but assisted living facilities often are not prepared to do such monitoring.

Although the assisted living industry can have a vital role to play in the needed array of long-term care services, it will fail if it is allowed or expected to be all things to all people. This is a situation that cries out for more precise regulatory standards than we see in most states, coupled with meaningful enforcement.

Sources:

[10] *See, e.g.,* Catherine Hawes, Charles D. Phillips & Miriam Rose, *High Service or High Privacy? Assisted Living Facilities, Their Residents and Staff: Results from a National Survey* (2000) (nationwide survey of more than 1,500 assisted living facilities, commissioned by U.S. Dept. of Health and Human Services), *available at* <http://aspe.hhs.gov/daltcp/reports/hshpes.htm> (executive summary).

[11] A pilot study was conducted of 5 assisted living facilities from April 1, 1997, to March 31, 1998, under the joint supervision of the Alabama Department of Public Health and the Alabama Department of Mental Health and Mental Retardation. The 5 facilities were permitted to admit residents with dementia to locked units. Changes in resident conditions were reported monthly and were closely monitored by both agencies. Almost from the outset, significant problems were noted in 4 out of 5 facilities in the areas of weight loss, falls with fractures, elopements, and resident on resident abuse and staff on resident abuse. The results of the study have not been published.

[12] Catherine Hawes, Charles D. Phillips & Miriam Rose, *High Service or High Privacy? Assisted Living Facilities, Their Residents and Staff: Results from a National Survey* (2000).

II. "Assisted Living" Must Be Defined In a Meaningful Way, and Governed By Standards That Guarantee a Reasonable Level of Quality.

A. Standards Are Needed To Assure an Adequate Quality of Care.

An older person generally moves into an assisted living facility because he or she no longer feels safe at home, or a family member believes that the older person is not safe at home. For example, this older person may have progressive dementia, suffer from urinary incontinence, or be partially paralyzed. He or she may need assistance in dressing, eating, toileting, or bathing, or have diminished sight or hearing. As is common, he or she may suffer from a chronic and potentially disabling disease such as diabetes, hypertension, or arthritis, and as a result would benefit from regular monitoring by a nurse.

Most likely, the older person never has lived in an assisted living facility, and knows little or nothing about long-term care options. More specifically, he or she likely knows little of what to expect from "assisted living."

For the benefit and protection of these vulnerable individuals, "assisted living" should be defined in a consistent and meaningful way, and assisted living law should establish standards that guarantee a reasonable level of quality. Following are examples of standards that should be set in law: it should be noted that this list is not all-inclusive and does not address resident rights and numerous other important areas of concern.

Levels of Care: As is explained in more detail in this paper's "level of care" discussion, assisted living law must specify the types of care that are mandated or prohibited in an assisted living setting. Vulnerable individuals seeking long-term care deserve a guarantee that certain services must be provided in an assisted living facility, and also deserve a clear explanation of what services cannot be provided. Some flexibility can be provided in the law – for example, different standards can apply to different levels of care within the assisted living category.

Staffing: Assisted living staffing too frequently falls at or below a bare minimum. A national study involving nearly 1,500 assisted living facilities found that "fewer than half of the residents reported that adequate numbers of staff were available at all times. . . . One third of the [facilities] had no registered nurse on staff, and one quarter had a ratio of one personal care assistant for each 23 or more residents."[13] Assisted living law should set standards for staffing and staff expertise, make those standards dependent upon residents' care needs, and require appropriate participation by nurses and other health care professionals. Alabama, for example, has specific standards for assisted living facilities that specialize in the care of residents with dementia. In Alabama's "Specialty Care" assisted living facilities, a physician coordinates medical care provided in the facility, and a registered nurse assesses resident needs. Alabama regulation sets minimum staffing levels to make sure that residents always have at least a respectable minimum of direct-care assistance.[14] Such standards can be – and should be – extended beyond dementia to assure that the care needs of all residents are met consistently.

Training of Direct Care Staff: Assisted living law should set requirements for basic training of direct care personnel. These requirements should include standards for trainer qualifications, as well as standards for course curriculum and competency testing.

Fire Standards: In just the past few months, several fires in long-term care facilities have killed and injured residents who were unable to escape due to physical disability or mental impairment.[15] Standards should be set that protect those residents who cannot protect themselves.

B. The Setting of Standards Should Not Be Left to a Facility's Contract.

Many assisted living providers claim that important assisted living issues should be determined by the facility's contract, rather than by regulation. Under such a model, a state's law would set few substantive standards, and instead would require that certain important issues be addressed in a facility's individual contract with a resident.

Such a contract-reliant model is wholly inadequate. It is grossly unfair to consumers.

The term "assisted living" becomes meaningless if it represents something different in each individual contract between a facility and a resident. Under a contract-reliant model, the contract of one "assisted living" facility could state that a dementia diagnosis is a reason for eviction, while the contract of a second "assisted living" facility could state that the facility can provide around-the-clock nursing care. For the benefit of consumers, there should be different terminology for facilities so dramatically different – for example, under the level-of-care system used in Florida, an assisted living facility can

Sources:

[13] Catherine Hawes, Charles D. Phillips & Miriam Rose, *High Service or High Privacy? Assisted Living Facilities, Their Residents and Staff: Results from a National Survey* 61-62 (2000).

[14] Ala. Admin. Code r. 420-5-20-.04.

[15] *See, e.g., Associated Press, Nursing Home Fire Search Warrant Issued*, Feb. 27, 2003 (ten persons killed in fire in nursing home in Connecticut); Nancy Wride, *Torrance Rest Home Fire Kills Two*, L.A. Times, Dec. 31, 2002.

be licensed for Limited Nursing Services or, in order to provide additional nursing services, can be licensed for Extended Congregate Services.[16]

Providers claim that assisted living contracts are "negotiated" with consumers but, in the real world, assisted living facilities prepare standard contracts, and those contracts are presented to incoming residents on a take-it-or-leave-it basis. In any case, it is unreasonable to expect an elderly individual in need of long-term care to negotiate the care that is needed and must be provided, or the standards that the facility should follow. This is particularly true in relation to the unknown and unpredictable needs that the resident likely will have in the future.

The danger of the contract-reliant model is shown by the continued emphasis by assisted living providers on the waiver-of-liability contractual provisions which euphemistically are known as "negotiated risk" or "shared responsibility."[17] Although providers suggest that these "negotiated risk" agreements are benign documents that allow a facility to honor a resident's preferences, "negotiated risk" actually refers to an agreement that allows an assisted living facility to admit or retain a resident whose needs the facility cannot meet, and that has the resident release the facility from any liability arising from the facility's inadequate care.[18] A public policy director for an assisted living corporation claims "that negotiated risk can protect [the] facility from regulatory action and/or litigation, and can justify non-intervention on the part of staff members."[19]

Source:

[16] Fla. Admin. Code Ann. r. 58A-5.030- 5.031.

[17] *See, e.g.*, Kenneth L. Burgess, Negotiated Risk Agreements In Assisted Living Communities (1999) (manual produced by Assisted Living Federation of America); Allen A. Lynch & Sarah A. Teachworth, *Risky Business: The Enforceability and Use of Negotiated Risk Agreements*, 1 Seniors Housing & Care Journal 3 (2002) (defense of negotiated risk agreements, authored by provider attorneys).

[18] *See, e.g.*, Joel S. Goldman, *Potential Legal Roadblocks Ahead for Assisted Living* in ALFA Fall 2001 National Conference & Expo Conference Proceedings 299 (Oct. 21-23, 2001), *as cited in* Allen A. Lynch & Sarah A. Teachworth, Risky Business: *The Enforceability and Use of Negotiated Risk Agreements*, 1 Seniors Housing & Care Journal 5 n.11 (2002); *see also* Eric Carlson, *In the Sheep's Clothing of Resident Rights: Behind the Rhetoric of "Negotiated Risk" in Assisted Living*, NAELA Quarterly, Spring 2003 (upcoming), *available at* <www.nsclc.org>.

[19] *Why Your Facility Should Have Negotiated Risk Agreements*, Briefings on Assisted Living, June 2000, <www.snfinfo.com/articles/BAL060001.cfm>, *reviewed on Internet on* April 3, 2003.

III. States Should Establish More than One Level of Assisted Living Licensure.

A. "One-Size-Fits-All" Does Not Fit Well.

States license assisted living facilities in order to protect the health and safety of residents, yet some state licensure systems apply "one-size-fits-all" standards to all assisted living facilities, regardless of the needs of the facility's residents. While a single standard may be appropriate for a facility whose residents have minimal needs, a single standard is simply inadequate to protect the increasing number of residents with significant physical and mental health care needs. Indeed, far from protecting the most vulnerable, a "one-size-fits-all" system reduces standards to the lowest common denominator.

In states with a single set of standards, assisted living providers set the range of services they will offer beyond those required for licensure, within any parameters (e.g., restrictions on the provision of certain services in assisted living) set by the state. Some providers offer only the minimum services required for licensure – meals plus limited supervision and assistance with routine activities of daily living. Others may serve residents with significant needs, including those with severe dementia and those whose care needs could justify nursing home care. Still others offer services somewhere between the two extremes, carving out certain services that they choose not to provide.

As discussed above, this model creates a system of standards set by contract and offers little protection to the consumer. In practice, consumers have no way of knowing whether providers have adequate staff to provide quality care, and no guarantee that the standard of care or the services offered will continue. Consumers are frequently frail, perhaps suffering from dementia, and their families are anxious and stressed. They generally are in no position to inquire about staffing or to understand the information they are given, to compare one facility to the next, or to understand pre-printed contracts that are long and complex.

B. Level-of-Service Licensing Enables Consumers to Make Meaningful Comparisons, and Facilitates Establishment of Appropriate Standards.

A more effective system is to avoid the "one-size-fits-all" model and instead license assisted living at more than one level, with levels defined by the type and severity of the physical and mental conditions of residents that the assisted living facility is prepared to accommodate. In a level-of-service licensure model, the state establishes two or three levels of licensure, each with certain requirements that providers must meet in order to be licensed at that level. Idaho and Maryland have established three levels of licensure based on services offered;[20] Arkansas, Florida, Mississippi, and Utah each have two levels.[21]

The most significant distinction between levels is in the health care provided. In Arkansas and Maryland, for example, Level I facilities are not permitted to administer medications; in Arkansas, only Level II facilities may house or provide services to residents whose medical needs would qualify them for nursing home care.[22]

Level-of-service licensure provides information that consumers otherwise would lack. By informing consumers what conditions a facility is or is not licensed to accommodate, a level-of-service system allows the consumer to choose a facility from the desired licensure category and, in deciding among facilities, to compare "apples with apples." Level-of-service licensure also allows states to establish appropriate standards for staffing levels and staff qualifications, special care or services, participation by health care professionals, and fire safety.

Level-of-service licensure benefits assisted living facilities by allowing them to choose what kind of services they will provide. Some may prefer not to offer a high level of services. Those opting to limit their services to meals, supervision, and limited assistance with activities of daily living would be licensed at a lower level. On the other hand, facilities desiring to continue serving residents whose needs increase could license at a higher level, allowing the facility to offer a full range of services from relatively low to high, under standards that help assure that a resident's needs will be met adequately.

Level-of-service licensure also can promote affordability in assisted living. It can limit the operating costs for facilities that choose not to offer more complex services. It also can limit expenses for private-pay consumers with fewer care needs, by allowing them the option of selecting (and paying for) a facility that offers only a lower level of service.

Sources:

[20] *See* Idaho Admin. Code § 16.03.22.400; Code Md. Reg. tit. 10, §§ 10.07.14 *et seq.*

[21] *See* Ark. Code Ann. §§ 20-10-1701 *et seq.*; Florida Stat. §§ 400.401 *et seq.*; Fla. Admin. Code Ch. 58A-5; Miss. Code Ann. § 43-11-1; Code Miss. R. 1202.1 *et seq.*; Utah Code Ann. §§ 26-21-1 *et seq.*, Utah Admin. Code 432-1-1.

[22] Ark. Code Ann. §§ 20-10-1701 *et seq.*; Md. Regs. Code tit. 10, § 10.07.14.04(F)(2)-(4).

In addition, level-of-service licensure can improve access to assisted living for low-income consumers, by encouraging facilities to participate in the Medicaid program. In most states, Medicaid funding can pay for assisted living services provided to Medicaid-eligible residents whose care needs could justify nursing home care. Licensure levels help a state to identify facilities appropriate for Medicaid payment, to assess whether residents in question will be provided the Medicaid-funded services. In Maryland, for example, Medicaid payment for assisted living services is available only to residents of Level 2 and 3 facilities.[23] In Arkansas, Medicaid payment is available only to residents of Level II facilities.[24]

Sources:

[23] While state policy does not specifically require Level 2 or 3 licensure as a condition of facility certification, as a practical matter only Level 2 and 3 facilities are licensed to provide the level of care required by the state Medicaid waiver program. *See* Md. Regs. Code tit. 10, § 10.09.54.16.

[24] Ark. Code Ann. §§ 20-10-1701 *et seq.*

IV. Assisted Living Facilities Should Be Subject To the Same Non-Discrimination Rules that Govern Nursing Homes, to Assure That Low-Income Medicaid Beneficiaries Are Treated Fairly.

A. The Medicaid Program Covers an Increasing Number of Assisted Living Residents.

Assisted living is moving rapidly beyond its initial identity as a housing option for relatively healthy and financially secure older people. The assisted living industry increasingly provides health care services, not just housing and personal care services, and it provides these services to a population that is becoming more frail and more similar to nursing home residents each year.

Under the banner of "affordable assisted living," and with the goal of extending the option of assisted living to a less wealthy clientele, the assisted living industry calls for public reimbursement of assisted living services. In practice, "affordable assisted living" translates into reliance on the Medicaid program to pay for health care services in assisted living facilities. Pursuant to federal Medicaid law, these Medicaid funds are used to pay for the care of residents suffering from medical conditions significant enough to warrant admission into a nursing home.

In fact, use of Medicaid money for assisted living care is expanding at a breakneck pace. Medicaid beneficiaries receiving assisted living as a Medicaid-funded service grew 70 percent between 2000 and 2002, from 60,000 to 102,000 individuals.[25] By October 2002, 41 states authorized their Medicaid programs to pay for assisted living services.[26]

B. Facilities Voluntarily Accepting Medicaid Payments Must Comply With Medicaid Requirements.

Participation in the Medicaid program is voluntary for a health care provider. In agreeing to accept Medicaid reimbursement, a health care provider promises to comply with program participation rules, including rules prohibiting discrimination against Medicaid beneficiaries, and protecting beneficiaries' limited income and savings.

Too commonly the assisted living industry wants the benefits but not the responsibilities of Medicaid reimbursement. But fairness to Medicaid beneficiaries – who, by definition, have few resources and limited incomes – demands that these standards be applied to and enforced in assisted living facilities.

C. Medicaid-Participating Facilities Should Be Required To Accept Medicaid From Residents Who Become Financially Eligible For Medicaid While Residing At the Facility.

A Medicaid-participating nursing home must accept Medicaid payment on behalf of a resident who becomes financially eligible for Medicaid during his or her stay.[27] A similar rule must apply in assisted living. It would be unconscionable to allow a Medicaid-participating facility to refuse Medicaid payment from a resident whose new Medicaid eligibility is the result of spending the last of his or her financial resources for assisted living care. If a facility were to be allowed to refuse Medicaid payment under such a situation, the resident inevitably would be evicted for nonpayment.

D. Medicaid-Participating Facilities Should Be Required To Accept Medicaid As Payment in Full for Covered Services.

To assure that Medicaid beneficiaries have full and independent access to care, longstanding Medicaid rules require Medicaid-participating health care providers to accept Medicaid as payment in full for Medicaid-covered services.[28] As a result, a Medicaid beneficiary can be required to pay only the deductibles and co-payments authorized by law.[29] In addition, Medicaid rules prohibit health care providers from soliciting or receiving payments from a beneficiary's family members or friends.[30]

These provisions establish a commonsense framework for public payments. By definition, Medicaid-eligible individuals are poor, and Medicaid rules require them to spend all their income – aside from a subsistence-level allowance – as a monthly deductible for Medicaid coverage. Without the legal protections, Medicaid-participating health care providers could restrict admission and services only to those Medicaid beneficiaries able to obtain supplemental payments from a family member or friend. If a beneficiary were unable to obtain supplemental payment, she would be denied necessary care and services.

These important protections must be extended explicitly to Medicaid-participating assisted living facilities. A Medicaid-participating facility must accept Medicaid payment as payment in full for Medicaid-covered services, and must accept a Medicaid beneficiary's available income – including federal and state income supplements under the Supplemental Security Income program – as sufficient payment for room and board. Once a facility has agreed to accept Medicaid reimbursement, the facility must not discriminate against Medicaid beneficiaries or Medicaid payment.

Sources:

[25] Robert L. Mollica, *Coordinating Services Across the Continuum of Health, Housing, and Supportive Services*, Journal of Aging and Health, vol. 15, no. 1, at 165, 172 (Feb. 2003).

[26] Robert L. Mollica, National Academy for State Health Policy, State Assisted Living Policy *ii* (2002) (within executive summary).

[27] 42 U.S.C. § 1396r(c)(4), (5)(A)(i); 42 C.F.R. § 483.12(c), (d)(1).

[28] 42 C.F.R. § 447.15.

[29] 42 U.S.C. § 1396a(a)(17).

[30] 42 U.S.C. §§ 1320a-7b(d), 1396a(a)(28), 1396r(c)(5)(A).

V. The Federal Government Should Take an Active Role In Assuring that Assisted Living Residents Receive Quality Care.

A. A U.S. Senate Committee Has Recognized the Need to Protect Assisted Living Residents.

In April 2001, the Senate Special Committee on Aging held a hearing entitled "Assisted Living in the 21st Century: Examining Its Role in the Continuum of Care." During the hearing, Senators repeatedly voiced questions and concerns about the well-being of vulnerable assisted living residents. For example, Senator Larry Craig (now Chairman) stated: "We must ask whether the States and the industry are doing enough to protect the elderly who rely on assisted living facilities." In a hearing a year later, Chairman John Breaux (now Ranking Member) noted many "unanswered questions" involving assisted living facilities "in terms of even what we call them, how we classify them, whether they are going to be State approved, federally approved, [and] whether States will have rules and regulations about the quality of care in these facilities."

During the 2001 and 2002 hearings, Senators have thought it premature to draft federal legislation governing assisted living. The Senators have noted, however, that if consensus on standards is not reached, it might be incumbent on Congress to act to ensure sufficient regulatory standards.

The April 2001 hearing was the genesis of the Assisted Living Workgroup which, despite a laborious process, has been unable to reach consensus on meaningful, enforceable standards for the assisted living industry.[31] Thus, many of the Senators' questions and concerns remain unresolved.

B. Existing Law Establishes Federal Jurisdiction Over Important Aspects of Assisted Living.

The federal government already has jurisdiction to address many problem areas in assisted living. For example, the Federal Trade Commission has authority to protect consumers from the false advertising and unfair and deceptive contractual provisions that have been observed in the assisted living industry.[32]

Some government jurisdiction is based on the significant amount of federal money paid for assisted living services. The ***housing*** costs of assisted living often are subsidized by payments or below-market loans from the Department of Housing and Urban Development, or the Department of Agriculture. The service costs of assisted living increasingly are funded by Medicaid or Medicare. Medicaid payments generally are made through "waiver" programs in which Medicaid covers all service costs (except for the resident's monthly deductible); other Medicaid programs pay only for certain health care provided to residents. Medicare payments generally cover certain health care reimbursable under Medicare Parts A and B.

C. The Federal Government Should Exercise its Authority to Ensure the Quality of Assisted Living Services Funded Through Medicaid Waivers.

As explained immediately above, the federal government has jurisdiction over numerous important aspects of assisted living, and federal funding is responsible for a significant percentage of assisted living care. And, of course, the health and safety of vulnerable assisted living residents is a pressing concern. All of these are compelling reasons for the federal government to take an active role in assisted living.

It is particularly appropriate that the federal government more diligently exercise its discretion in evaluating Medicaid waiver applications. The "waiver" of Medicaid law allows states to establish assisted living facilities as an alternative to nursing homes. Waiver reimbursement is reserved only for those Medicaid beneficiaries whose medical needs are severe enough to warrant nursing home care.[33] Currently federal Medicaid waivers pay for assisted living services for 102,000 residents in forty-one states, establishing the federal government as a major purchaser of assisted living services.[34]

Under existing law, the federal government has broad discretion that can be exercised to respond to the vulnerable condition of residents receiving assisted living services under a Medicaid waiver. The relevant federal statute requires states to establish "necessary safeguards . . . to protect the health and welfare of individuals provided services under the waiver and to assure financial accountability for funds expended with respect to such services."[35] The corresponding federal regulation requires "adequate standards" along with enforcement of the relevant state licensure rules.[36] Under this federal law, the federal government has authority to be more discriminating in evaluating the state standards applicable to the more health-impaired population that receives assisted living services through a Medicaid waiver.

Sources:

[31] *See* Assisted Living Workgroup Final Report to the U.S. Senate Special Committee on Aging (April 2003), *available at* <www.alworkgroup.org>.

[32] See 15 U.S.C. §§ 45, 52-54, 57a, 57b (FTC authority); *see also* General Accounting Office, Quality-of-Care and Consumer Protection Issues In Four States, Report No. HEHS-99-27 (1999) (*vague and misleading advertising and* contracts in assisted living).

[33] *See* 42 U.S.C. § 1396n(c).

[34] Robert L. Mollica, *Coordinating Services Across the Continuum of Health, Housing, and Supportive Services*, Journal of Aging and Health, vol. 15, no. 1, at 165, 172 (Feb. 2003); Robert L. Mollica, National Academy for State Health Policy, State Assisted Living Policy ii (2002) (within executive summary).

[35] 42 U.S.C. § 1396n(c)(2)(A).

[36] 42 C.F.R. § 441.302(a)(1), (2).

VI. Conclusion.

"Assisted living" is an attractive and appealing term. But to this point the reality of assisted living has fallen far short of the images evoked by the term.

Assisted living standards must be strengthened so that the term "assisted living" has real meaning. These standards should define levels of care within the broad category of assisted living, so that consumers can choose among like facilities. Within each level, these standards should ensure that the staff is adequate in numbers and expertise to address residents' needs. Also, these standards should require that low-income Medicaid recipients be treated fairly, and pay particular attention to the needs of those health-impaired individuals whose care is reimbursed through Medicaid waivers.