

Promise and Pitfalls in Assisted Living

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STATE ASSISTED LIVING LAWS FREQUENTLY GIVE EXCESSIVE FLEXIBILITY TO FACILITIES.¹

Many Variations from State to State, and Also Within States

Assisted living facilities offer residential care and services for older persons who are unable to live independently. Some residents require relatively limited assistance with dressing, bathing, or other activities of daily living. Other residents, however, require significantly more assistance, and many require health care services on an ongoing basis. For example, some residents are non-ambulatory or incontinent, and others require oxygen administration or treatment for pressure sores.

Assisted living facilities are licensed by individual states under laws developed by those states. Terminology varies from state to state; these types of facilities are variously denominated as (for example) assisted living facilities, assisted living residences, or personal care homes.

In some states, the specifics of assisted living depend significantly on the admission agreement between the facility and resident. Illinois, for example, follows a contract model that goes so far as to suggest that residents may contract to inadequate care, through the law's supportive attitude towards residents accepting risk:

Assisted living, which promotes resident choice, autonomy, and decision making, should be based on a contract model designed to result in a negotiated agreement between the resident or the resident's

¹ This discussion of state law is adapted from Best Practices in Assisted Living: Considering Potential Reforms for California, a Justice in Aging publication written by Eric Carlson.

representative and the provider, clearly identifying the services to be provided. ... This model supports the principle that there is an acceptable balance between consumer protection and resident willingness to accept risk and that most consumers are competent to make their own judgments about the services they are obtaining.²

This attitude towards risk is inappropriate, as a matter both of policy and law. Reliance on contract provides insufficient assurance that the facility will provide an appropriate level of care. Also, assumption of risk generally is limited to optional, risky activities such as downhill skiing and skydiving, and when applied to health care has been found by courts to violate public policy.³

Many states offer broad definitions of assisted living, encompassing as a practical matter many facilities that offer significantly different levels of care. California provides one example, defining its “residential care facilities for the elderly” as a:

housing arrangement chosen voluntarily ... where varying levels and intensities of care and supervision, protective supervision, or personal care are provided, based upon their varying needs, as determined in order to be admitted and to remain in the facility.⁴

This type of broad definition presents significant problems. Consumers will assume, wrongly, that status as assisted living facility guarantees more than it actually does.

² 210 Illinois Statutes 9/5.

³ Eric Carlson, Protecting Rights or Waiving Them? Why “Negotiated Risk” Should Be Removed from Assisted Living Law, 10 J. Health Care L. & Pol’y 287 (2007).

⁴ Cal. Health & Safety Code § 1569.2(o)(1).

Also, facilities may attempt to evict unwanted residents by declining to provide a service that the resident needs.

With a broad definition, quality of care regulations often are inadequate, since they are largely based on the lowest-common-denominator of facilities providing low levels of care. In a related matter, the law may be difficult to reform to address such problems; reform initiatives tend to be stymied by arguments from low-level-of-care facilities that they don't need or can't afford the proposed reform.

These problems can be ameliorated if the state offers multiple levels of care within the assisted living category. For example, New York licenses assisted living while giving providers the option of obtaining additional certification for "enhanced" assisted living, or assisted living with care of "special needs." Under "enhanced" assisted living, the facility's staff is authorized to provide additional care to meet the needs of residents who (for example) need assistance to walk, are incontinent, or depend upon medical equipment. "Special needs" facilities focus on care of residents with particular conditions; generally these are facilities specializing in dementia care.⁵

Mississippi licenses two types of facilities: "personal care homes - assisted living" and "personal care homes - residential living." The primary difference between the two is that certain health-related services (medication administration, for example) can be made available in personal care homes - assisted living.⁶

⁵ N.Y. Comp. Codes R. & Regs. tit. 10, §§ 1001.2, 1001.5.

⁶ Code Miss. R. 15 016 047 §§ 5.1 – 5.2, 15 016 048 § 2.2.

Assisted Living Should Incorporate Health Care Expertise.

Today's assisted living facilities house many residents who, in past years, would have resided in nursing facilities. As the years have gone by, state laws increasingly have allowed increased admission and retention of residents with significant health care needs. It's noteworthy that many assisted living facilities accept reimbursement through Medicaid Home and Community-Based Services waivers, and a condition of eligibility for those waivers is that the beneficiary require care at a nursing facility level of care.⁷

This increase in resident acuity has led to greater incorporation of health care in assisted living, most notably through nursing services requirements. Connecticut is one of the states that give nurses a significant role in assisted living. Connecticut licenses assisted living services agencies, rather than facilities; in part because of this different orientation, the state's rules have a greater focus on nurses and nursing services. Each assisted living services agency must have written policies regarding the delivery of nursing services. Nursing services include hands-on services, medication administration, disease prevention, wellness counseling, and health promotion. A registered nurse also is responsible for a variety of other important tasks including assessments, service coordination, training, and discharge planning.⁸

In Kansas, if a functional capacity screening has indicated a need for health care services, a nurse participates in developing a health care service plan. Then the nurse

⁷ 42 U.S.C. 1396n(c)(1).

⁸ Conn. Agencies Regs. § 19-13-D105(a)(2), (h)(1), (3).

provides any skilled nursing care that may be required, along wellness and health monitoring as specified in the resident's service agreement.⁹

In Arkansas, a Level II facility must employ or contract with licensed nurses to provide nursing care and direct care services, including medication administration. In addition, a Level II facility must employ or contract with at least one registered nurse. The registered nurse is responsible for the preparation, coordination and implementation of a resident's direct care services plan, and also reviews and oversees all direct-care staff. The registered nurse need not be physically present at the facility, but must be available by phone or pager.¹⁰

Despite the increase in resident acuity, provider representatives often object to proposed requirements for health care expertise (such as nurse staffing) by claiming that assisted living is based on a social model rather than a medical model, and that imposition of health care requirements would improperly tend to make assisted living facilities too much like nursing facilities. Such arguments should be rejected. As mentioned, assisted living residents increasingly have health care needs, and those needs should be met. The either/or framing of the social model versus the medical model is deceptive, because a facility should be able to offer both health care expertise and a good quality of life.

⁹ Kan. Stat. Ann. § 39-923(5); Kan. Admin. Regs. § 26-41-204(b), (g)-(h).

¹⁰ Code Ark. R. § 20-411-402, -403.

FEDERAL LAW SETS LIMITED STANDARDS FOR FACILITIES ACCEPTING MEDICAID HCBS REIMBURSEMENT.¹¹

State Medicaid programs generally can pay for assisted living care through Medicaid home and community-based services (HCBS). If a facility is certified to accept Medicaid HCBS payment, it must comply with relevant federal law, specifically the HCBS Settings Rule that was promulgated in 2014 and became effective in 2023.¹² The standards apply to all settings in which Medicaid HCBS recipients receive HCBS, including private homes, day centers, and residential facilities. Certain of the standards apply only to the residential facilities, which are described in the regulations as “provider-owned or controlled residential settings.”¹³ This term includes assisted living facilities, and also facilities for adults or children with disabilities, such as group homes.

To this point, the federal law has been poorly implemented and enforced, so violations of the federal law may be relatively common. Here are some common violations, along with explanations of the relevant law.

¹¹ This discussion of federal law is adapted from Rights and Wrongs in Medicaid-Funded Assisted Living, a Justice in Aging publication written by Eric Carlson.

¹² See 42 C.F.R. § 441.301(4), (5); 79 Fed. Reg. 2948 (2014). Section 441.301 applies to settings reimbursed through Medicaid HCBS Waivers. The same regulatory language is repeated in other sections of the CFR to cover settings reimbursed through the Community First Choice Option or the HCBS state plan benefit. See 42 C.F.R. §§ 441.530(a)(1) (Community First Choice Option), 441.710(a)(1) (HCBS state plan benefit).

¹³ See 42 C.F.R. § 441.301(4)(vi).

Violations Relating to Autonomy and Privacy

Freedom in Schedules and Activities

Wrong: A resident cannot do longtime exercises because the facility does not make appropriate space available.

Correct: Under federal regulations, a resident must “have the freedom and support to control their own schedules and activities.”¹⁴ Accordingly, the facility should arrange for an appropriate space to be made available for an adequate number of days per week, with sufficient time per session.

Privacy

Wrong: Residents share a bedroom with no barrier between them.

Correct: Federal regulations require that “[e]ach individual has privacy in their sleeping or living unit.”¹⁵ A shared bedroom, at a minimum, must have a curtain for visual privacy.

...

Wrong: Facility staff go in and out of a resident’s room whenever they please.

Correct: Entrance doors to the living unit must be lockable by the resident, with only appropriate staff having keys. Because residents have a right to privacy, staff should knock and ask permission to enter, even if the door is unlocked or they have a key.¹⁶

¹⁴ 42 C.F.R. § 441.301(4)(vi)(C).

¹⁵ 42 C.F.R. § 441.301(4)(vi)(B).

¹⁶ 42 C.F.R. § 441.301(4)(vi)(B)(1).

Choice of Roommates

Wrong: The facility tells a resident that a roommate is moving into the living unit tomorrow.

Correct: Federal regulations say: “Individuals sharing units have a choice of roommate in that setting.”¹⁷ Accordingly, the facility should consult with all affected residents in deciding who will be sharing with whom.

Decorating and Furnishing Living Unit

Wrong: The facility tells a resident that they cannot bring in furniture or hang anything on the walls.

Correct: A resident has the right under federal regulations to furnish and decorate their living unit.¹⁸

Access to Food

Wrong: The facility serves breakfast, lunch and dinner, but offers no snacks or other food.

Correct: Under federal regulations, a resident must “have access to food at any time.”¹⁹ Food should be available whenever a resident may want something to eat, night or day. Furthermore, for this right to be meaningful, food options should be reasonably

¹⁷ 42 C.F.R. § 441.301(4)(vi)(B)(2).

¹⁸ 42 C.F.R. § 441.301(4)(vi)(B)(3).

¹⁹ 42 C.F.R. § 441.301(4)(vi)(C).

appropriate and appealing. It would not be adequate, for example, for a facility to claim compliance by leaving out a few bags of snack crackers.

Access to the Community

Wrong: When a resident says they want to leave the facility (go shopping, attend church service, etc.), the facility's only assistance is to provide the resident with a city bus schedule. Or possibly the facility will provide transportation but only one morning a week, and only to one shopping center.

Correct: The facility must support residents' "full access" to the community, including the ability to engage in community life and receive services.²⁰ The level of needed support will vary with the resident, and could include transportation and hands-on assistance.

Right to Accept Visitors

Wrong: The facility sets visiting hours from 10 a.m. to 8 p.m.

Correct: Under federal regulations, a resident has a right "to have visitors of their choosing at any time."²¹ "Any time" must mean exactly that: 7 days a week, 24 hours a day. If a resident with a shared living unit chooses to accept a visitor when the roommate is sleeping, the resident and facility should arrange for an appropriate place for the visit, away from the sleeping roommate.

Physical Access and Freedom to Move

Wrong: The bathroom door is too narrow for a resident's wheelchair.

²⁰ 42 C.F.R. § 441.301(4)(i).

²¹ 42 C.F.R. § 441.301(4)(vi)(D).

Correct: Under the federal regulations, the facility must be “physically accessible” to the resident.²²

...

Wrong: Using a vest restraint, the facility prevents a resident from leaving their chair.

Correct: Facilities cannot use physical restraints: federal regulations guarantee “freedom from coercion and restraint.”²³

Evictions, & Unit-to-Unit Moves Within a Facility

Wrong: The facility tells a resident that they are being evicted and have no right to appeal.

Correct: The resident must have eviction protections and appeal rights comparable to a tenant’s rights under the state’s landlord/tenant law. Either the state’s landlord/tenant law includes assisted living or, if not, a written residency agreement with the facility must create comparable protections.²⁴

...

Wrong: A resident has been paying the private-pay rate for one year but, after spending down savings, now is eligible for the HCBS program. The facility refuses HCBS Medicaid from the resident and says that the resident has to pay the private-pay rate or

²² 42 C.F.R. § 441.301(4)(vi)(E).

²³ 42 C.F.R. § 441.301(4)(iii).

²⁴ 42 C.F.R. § 441.301(4)(vi)(A).

move out, claiming that the admission agreement obligates the resident to pay the private-pay rate for at least 18 months before converting to Medicaid.

Correct: Because the facility is Medicaid-certified, a federal regulation (not part of the Settings Rule) requires that the facility accept Medicaid as payment in full.²⁵ This follows the general rule that when a health care provider is certified for a patient's health care coverage (Blue Cross, for example), the provider must not charge the private-pay rate and must instead bill the insurance coverage.

...

Wrong: The facility tells a resident that they must move from one living unit to another.

Correct: Under the federal regulations, the living unit is a "specific physical place" rented under a "legally enforceable agreement."²⁶ The resident's situation is comparable to living in an apartment. Just as a landlord generally cannot force an apartment tenant to move from one apartment to another, an assisted living facility cannot force a resident to move to a different living unit.

Legal Protections Under Some Circumstances Can Be Reduced Through Individual Service Plans.

Under limited circumstances, some of the resident rights discussed above can be reduced through the resident's service plan, which is developed by the agency

²⁵ 42 C.F.R. 447.15.

²⁶ 42 C.F.R. § 441.301(4)(vi)(A).

operating the HCBS program. Specifically, only the following legal protections can be reduced:

- Rental of a “specific physical space” in the facility.
- Eviction protections comparable to protections available under landlord/tenant law.
- Lockable doors.
- Choice of roommate.
- Decorating and furnishing living unit.
- Freedom and support to control schedules and activities.
- Visitors at any time.

Importantly, reductions to legal protections are allowed only after the facility first has tried “less intrusive methods,” and only if the resident (or resident’s representative) agrees to the reduction. Any reduction must be proportionate to the relevant issue, so the resident loses legal protection only to the extent necessary.²⁷

Note some ambiguity in the potential reduction of a resident’s privacy rights. While the protection for “privacy in their sleeping or living unit” can be reduced, no reduction is authorized for a broader requirement that a facility ensure the resident’s “rights of privacy, dignity and respect.”²⁸

Remember that legal protections can be reduced under a service plan only if the resident (or resident’s representative) consents. If a resident does not want a legal

²⁷ 42 C.F.R. § 441.301(4)(vi)(F).

²⁸ 42 C.F.R. § 441.301(4)(iii), (vi)(B).

protection reduced, they should give the facility clear written notice that they do not consent to any reduction.

When a Facility Violates the Federal Law

Ideally, the state assisted living licensing agency will have authority to enforce the relevant federal laws. In many cases, however, authority to enforce the federal regulations will rest with the state Medicaid agency, which may not yet have a good enforcement mechanism. The majority of these federal regulations did not become effective until March 2023. State Medicaid agencies are required to establish grievance systems for their HCBS programs by July 2026, but the Centers for Medicare & Medicaid Services has told states that they won't enforce this requirement until (at the earliest) January 2028.²⁹

Because of the relatively recent effective date, many state enforcement systems are extremely limited at this time. Systemic advocacy is sorely needed. Residents, resident representatives, and resident advocates should advocate with state officials to create effective systems for accepting consumer complaints and enforcing federal regulations against noncompliant facilities.

²⁹ 42 C.F.R. § 441.301(c)(7); 89 Fed. Reg. 40,542, 40,550 (2024); CMS, CMCS Informational Bulletin, Exercise of Enforcement Discretion for Requirements for a Medicaid Fee-For-Service (FFS) Grievance System for Home and Community-Based Services (HCBS) Until December 2027 (Feb. 26, 2026).