

Assisted Living Roundtable
Senate Special Committee on Aging
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Responses to Written Questions

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Assisted Living Consumer Alliance,
Center for Medicare Advocacy, and
National Consumer Voice for Quality Long-Term Care**

1. *What are some of the leading state models with regard to consumer disclosure standards – e.g., of nursing staff availability, and staff training; charges for services, and charges for other (non-services) benefits; and protocols for individual assessments?*

A number of states have developed disclosure forms which provide consumers with a range of information. Two examples of forms are the forms used by Texas and Washington. See Texas Assisted Living Disclosure Statement, Form 3647, www.dads.state.tx.us/forms/3647/3647.pdf; Washington Disclosure of Services, DSHS 10-351, www.dshs.wa.gov/pdf/ms/forms/10_351.pdf. Each of these forms provides some helpful information, although each also has significant limitations.

Disclosure should include information such as the following:

- Overview of state requirements for levels of care and mandatory services.
- Assessment and care planning procedures.
- Detailed information on services provided in areas such as
 - Nursing care.
 - Personal care.
 - Dementia care.
 - Dietary services.
 - Medication administration and other assistance with medication.
 - Transportation.
 - Resident Activities.
- Staff training levels.
- Staffing patterns, including ratio of direct-care staff members to residents. (The last page of the Texas disclosure form contains a table of Shift Times and Staffing Patterns at the Facility.)
- Criteria for involuntary transfer or discharge, and any appeal rights that the resident may have.
- Certification for Medicaid, or lack thereof.
- Services included in the facility's base rate.
- Charges for any services not included in the facility's base rate.
- Room hold policies during hospitalizations.
- Deposits, and refund provisions related to deposits.

Although disclosure forms can be helpful to consumers searching for an assisted living facility, disclosure cannot substitute for legal standards. When looking for a long-term care facility, consumers generally are not prepared to distinguish between different facilities in this way, due to unfamiliarity with the relevant issues, and to the stress and time pressure that often accompany a search.

Of course, all disclosure items must be consistent with state licensure standards and any other legal standards.

2. *What are the essential services, the core philosophy, and other key characteristics of assisted living that allow residents to have independence, privacy, autonomy and choice? Are there ways of defining assisted living in a way that meets the needs and preferences of all populations that are eligible for Medicaid HCBS services?*

Private occupancy is the most important characteristic. Also, the unit or room should be a specific physical space owned or rented by the person

receiving services, with this person having at a minimum the same protections from eviction that the state’s tenants have under landlord/tenant law. Residents should have the freedom to furnish and decorate their own units.

Residents should have the freedom and support to control their own schedules and activities, and have access to food at any time. Residents also should be able to have visitors of their choosing at any time.

A facility should be responsible for making reasonable accommodations for a resident’s needs. A facility’s scheduling should be driven by residents’ needs rather than by the convenience of the facility or its staff members.

A facility’s services should facilitate residents’ engagement with and participation in the community. Residents should be provided with necessary transportation to access services and activities in the community.

Currently the term “assisted living” is used in confusing ways to refer to everything from facilities that provide little more than room and board to those that provide around-the-clock nursing care. More definitional clarity and precision are needed, addressing both resident autonomy and care standards. For purposes of facilities that provide care under Medicaid HCBS waivers, assisted living should be defined to ensure care standards that will be adequate for residents whose care needs would warrant nursing facility care.

Definitions should be written with specificity as to resident rights and facility requirements. It is not enough to list a particular philosophy of care—the definition must be substantive and specific enough to ensure that a philosophy will be actualized and enforceable.

3. *Are there ways that states have developed to balance ensuring quality of assisted living services under Medicaid, while not treating it differently from other home and community-based services? What is the role of state oversight in this regard?*

We believe that Medicaid programs *should* treat assisted living facilities differently than the programs treat other providers of home and community-based services. Assisted living facilities provide around-the-clock care along with housing, meals, and other services. An assisted living facility is far different from (for example) a personal care provider who assists a Medicaid beneficiary for a few hours daily in the beneficiary’s own home.

Currently, in most cases, certification of a facility for Medicaid participation under an HCBS waiver does not change the relevant quality of care standards for that facility in any significant way. In the HCBS Waiver Application submitted by states, Appendix G lists participant safeguards and Appendix H lists the state's Quality Management Strategy. Appendix G concerns itself with only three limited areas: State Response to Critical Events or Incidents, Safeguards Concerning Restraints and Restrictive Interventions, and Medication Management and Administration. For these areas, a state generally refers to the state's existing licensure standards, without establishing any additional standards. Appendix H also does not include any quality standards, and instead has states lay out a system of data collection, analysis, and remediation.

By definition, HCBS waiver services are provided only to persons who have care needs that would qualify them for nursing facility admission. Given these increased care needs, and the significant amount of federal money spent on HCBS in assisted living facilities, it would be appropriate for CMS at a minimum to establish some limited standards for Medicaid-funded assisted living care.

4. *Are there key physical plant features that generally distinguish assisted living from an institutional nursing facility model, and which are common between states, or is there great variation? From a board and care model?*

Originally, one of the biggest distinctions between the nursing facility model and the assisted living model was the private occupancy to be offered by assisted living facilities. This is still largely true in the private-pay market: private occupancy is the norm for residents paying privately for their care, as they prefer private occupancy and can pay for it.

By and large, however, state assisted living laws do not require private occupancy, and neither do Medicaid laws and policies. For Medicaid payment for assisted living services, many Medicaid HCBS waivers state that a resident in that state is entitled to a private unit, unless two residents agree to share a unit. Nonetheless, in practice, shared occupancy is the norm under such waivers. The facilities are set up to provide shared occupancy to Medicaid-eligible residents, and the residents "agree" to shared occupancy because they effectively do not have an available alternative.

It is difficult to generalize regarding the size of an assisted living facility's physical plant. Some assisted living facilities house over one hundred residents. Others may house six or seven residents in a converted house in a residential neighborhood.

5. *Are there any minimum (explicit or implicit) federal expectations or requirements for state oversight and monitoring of assisted living?*

In most states, Medicaid money for assisted living is provided through a Home and Community-Based Services (HCBS) waiver. Because HCBS waivers are not exclusively for assisted living—most HCBS waivers cover services provided in a beneficiary's home—HCBS waivers for assisted living in general do not set standards for oversight and monitoring of assisted living. Instead, the HCBS waiver defers to the state assisted living licensure standards, with the federal government accepting the existence of state licensure standards as adequate consumer protection, regardless of the quality of those licensure standards or their actual enforcement.

In the HCBS Waiver Application submitted by states, Appendix G lists participant safeguards and Appendix H lists the state's Quality Management Strategy. Appendix G concerns itself with only three limited areas: State Response to Critical Events or Incidents, Safeguards Concerning Restraints and Restrictive Interventions, and Medication Management and Administration. Appendix H does not include any quality standards, and instead asks states to lay out a system of data collection, analysis, and remediation.

6. *[no answer submitted]*

7. *[no answer submitted]*

8. *[no answer submitted]*

9. *How are HUD and HHS collaborating to better connect housing and services for person[s] with disabilities and older adults—including the recent provision of funding for 1,000 housing vouchers to serve non-elderly disabled individuals transitioning from institutions? Will these vouchers be used for subsidization of rent only, and if so, how will the services be paid for?*

HUD and HHS have created the Community Living Initiative to assist people with disabilities in moving out of institutions and integrating into the community. Information about the initiative is available at www.hhs.gov/od/topics/community/olmstead.html.

HUD on April 7, 2010, announced the availability of 5,300 vouchers to be used by public housing agencies to provide housing for non-elderly persons with disabilities. The Notice of Funding Availability divided the vouchers between approximately 4,300 Category 1 vouchers and 1,000 Category 2 vouchers. To obtain Category 1 vouchers, the public housing agency must demonstrate that tenants will have access to adequate support services. The standards for obtaining Category 2 vouchers are higher: the public housing agency must identify a partnering agency, and that agency must be a state-level agency responsible for transferring persons out of nursing facilities and like institutions. In most cases, this partnering agency will be the agency responsible for transferring persons from nursing facilities under the state's Money Follows the Person (MFP) program.

Vouchers can be used for housing but not services. MFP programs help pay for transition expenses. Medicaid HCBS programs often are used to pay for ongoing personal care expenses.

10. *[no answer submitted]*

11. *[no answer submitted]*

12. *[no answer submitted]*

13. *Are there estimates of how many Medicaid beneficiaries who are served in nursing homes today could be served in assisted living residences instead? What would be the cost savings to states and the federal government if more affordable assisted living was available?*

Making such an estimate is complicated by the fact that assisted living facilities can vary greatly from each other, both from state to state and within a single state.

14. *Are there changes in Medicaid that the federal government and states could make that would make it more feasible to finance and develop affordable assisted living? For example, if states work to develop significant home and community-based state options that are not subject to hard enrollment caps, might this enhance interest in expanding assisted living among developers and advocates?*

Eliminating enrollment caps clearly would be one way to make affordable assisted living a more viable option for residents, providers, and developers. A state's care system is improperly skewed towards nursing facility care if nursing facility care is an entitlement but Home and Community-Based Services (HCBS) in an assisted living facility are subject to an enrollment cap.

Also, protections against spousal impoverishment should be made mandatory in HCBS programs as soon as possible. Under 2010's health care reform law, the protections against spousal impoverishment are scheduled to become mandatory for HCBS programs in 2014, but that does not help those at-home spouses who are becoming impoverished now, or those Medicaid beneficiaries who are staying in a nursing facility rather than a Medicaid-certified assisted living facility in order to protect the at-home spouse from impoverishment.

Finally, state Medicaid programs should establish realistic room and board allocations for beneficiaries living in assisted living facilities. Currently, room and board allocations too often are based on Supplemental Security Income (SSI) levels, rather than on the cost of providing room and board. Adequate room and board standards would allow the resident to retain additional income, and authorize the facility to charge the resident a higher amount consistent with the income retained by the resident. This issue is discussed in somewhat more detail in question (and answer) #15, immediately below.

15. *Are there states that set their Medicaid rates for assisted living to factor in an annual measure of inflation? Are there states that have examined Medicaid reimbursement levels in the context of what providers' costs are for room and board and services?*

We defer to other roundtable participants as to the Medicaid service rates used by specific states. We note that a Medicaid-certified assisted living facility receives two types of payments: one for room and board, and the other for services. Because the Medicaid program does not pay for room and board in an assisted living setting, the room and board payment is made by the resident from the resident's available income, at an amount set by the

state. Payment for services is made by the Medicaid program and also by the resident, if the resident's income exceeds a minimum set by the state.

In sum, the resident pays the room and board charge, and may also contribute towards assisted living services, if the resident's income is high enough. The resident's payments for room and board and for services are calculated to leave the resident with a small monthly personal needs allowance, generally in the range of \$60 to \$100 monthly.

In general, the room and board rates used by state Medicaid programs are unrealistically low. They often are based on SSI payment levels rather than on the facility's cost of providing room and board.

16. *How common is the practice of Medicaid-participating facilities seeking additional (supplemental) funding from a beneficiary's family? What is the extent of private supplementation currently?*

Based on our conversations with consumer representatives from across the country, this type of supplementation is not uncommon. We are not aware, however, of any good empirical measure of the extent of supplementation. The state and federal governments do not compile that information, to our knowledge. Even if there were an attempt to gather such data, the results might not be accurate: "supplemental" payments are often made surreptitiously, in an effort to keep that payment from reducing or eliminating the resident's eligibility for Supplemental Security Income (SSI) or Medicaid.

The federal and state governments should prohibit assisted living facilities from soliciting or accepting supplemental payments from the family or friends of a resident eligible for SSI or Medicaid, unless the supplemental payment truly is for an "extra" item or service not covered under the facility's basic services or the Medicaid service package. By definition, residents eligible for SSI and/or Medicaid have few savings and very limited income, and a facility should accept the state-authorized amount as payment in full.

If a facility has chosen to be certified as a Medicaid provider, it has agreed to accept Medicaid-authorized amounts as payment in full for Medicaid-covered services. See Section 447.15 of Title 42 of the Code of Federal Regulations. It is unfair to Medicaid beneficiaries, and a violation of federal Medicaid law, for a facility to solicit or accept supplemental payments from the family members or friends of a Medicaid-covered resident.

The National Senior Citizens Law Center recently published a white paper on this issue, entitled *Medicaid Payment for Assisted Living: How Supplemental*

Payments Affect an Assisted Living Resident's Eligibility for Medicaid and SSI. A copy of this white paper is submitted with these answers.

17. *Do states generally require Medicaid-participating assisted living facilities to disclose what their policies are with regard to retaining residents who spend down their private funds and become eligible for Medicaid? Do states generally allow facilities to discharge individuals who start out as private-pay clients and spend down to Medicaid eligibility over time, e.g., when the facility is in a position to replace a Medicaid beneficiary with a resident who can afford to pay a higher rate?*

Protections in this area are vitally important. A resident is placed in a serious predicament if she spends her life savings for assisted living care, only to be told, after savings have been spent, that the Medicaid-certified facility has decided to not accept Medicaid for her care.

Federal law should offer protection to residents, but neither CMS nor the state Medicaid agencies seem to be applying the federal law to assisted living facilities. The relevant authority is section 447.15 of Title 42 of the Code of Federal Regulations, which broadly requires a Medicaid-certified provider to accept Medicaid reimbursement from a Medicaid-covered patient. For example, if a Medicaid-certified hospital provides services to a Medicaid-covered patient, the hospital must accept Medicaid reimbursement (plus any authorized patient contribution) for that patient's care. The hospital is not allowed to bill the resident on a private pay basis.

This federal requirement, unfortunately, often does not seem to be enforced in the case of Medicaid-certified assisted living facilities. For example, over the past two years the Assisted Living Concepts (ALC) chain has implemented a national strategy of refusing to accept Medicaid from residents in Medicaid-certified facilities, in order to drastically reduce the percentage of ALC's residents under Medicaid coverage. *See, e.g.,* N.J. Dep't of the Public Advocate, *Aging in Place, Promises to Keep, An Investigation into Assisted Living Concepts, Inc. and Lessons for Protecting Seniors in Assisted Living Facilities* (2009), at www.state.nj.us/publicadvocate/seniors/pdf/alc_report.pdf.

Thus, disclosure of policies is not an adequate protection for residents, if the disclosure gives a Medicaid-certified facility the option to refuse Medicaid reimbursement from a Medicaid-covered resident in the future. Potential residents instead deserve a clear message when looking for and then choosing an assisted living facility – a message that either the facility is not certified for Medicaid and will not be able to accept Medicaid reimbursement

if and when the resident becomes Medicaid-eligible, or the facility is certified for Medicaid and will be able to accept Medicaid.

Most state Medicaid programs do not have a clear position on this issue, and that lack of clarity as a practical matter allows a facility to refuse Medicaid from a resident as the facility chooses. Disclosure is required in a limited number of states including New Jersey and Oregon.¹ As mentioned, disclosure alone is inadequate protection for consumers. In 2008, the National Senior Citizens Law Center obtained assisted living disclosure statements through New Jersey's Open Public Records Act. According to the disclosure statements, the state's facilities imposed onerous requirements for acceptance of Medicaid: forty-five percent of the facilities would not accept Medicaid unless the resident had already paid on a private-pay basis, and, of those facilities, a full 82 percent required private payment of at least ten months.

The National Senior Citizens Law Center recently published a white paper on this issue, entitled *Medicaid Payment for Assisted Living: Preventing Discrimination against Medicaid-Eligible Residents*. A copy of this white paper is submitted with these answers.

18. *Is it common for states to have processes in place that permit Medicaid beneficiaries to appeal discharge decisions by assisted living facilities?*

No, it is not common. In the HCBS waiver application, the state must list its appeal processes in Appendix F, but those appeal processes apply to a resident's appeal of the state's decision whether or not to grant waiver eligibility. Those appeal processes do not apply to an assisted living facility's decision to discharge a resident.

¹ N.J. Dep't of Health & Sen. Servs., Div. of Aging & Community Servs., Policy Memorandum # 2004-5, VIII-1, Disclosure of Assisted Living Facilities' Medicaid Policies (July 30, 2004); Or. Dep't Hum. Servs., Div. of Seniors & People with Disabilities, Uniform Disclosure Statement: Assisted Living/Residential Care Facility, Form SDS 9098A (Feb. 2008); *see also* Or. Admin. R. 411-054-0025(7).

19. *What is the legal position of facilities licensed to offer assisted living services with regard to discharging residents who say they do not wish to leave, but whose needs exceed state-licensed “level of care” requirements, under federal anti-discrimination statutes, including the Americans with Disabilities Act, the Fair Housing Act and Fair Housing Amendments?*

In such a situation, the facility will be expected to comply with the licensing level of care requirements. If the resident contends that the level of care requirements violate federal law, the burden will be on the resident to file suit against the state under the federal law in order to invalidate the improper level of care requirements. The facility likely would be named also in such a suit, but as a practical matter there likely would be no obligation placed against the facility unless and until the state were ordered to reform its level of care requirements.

If state law authorized a facility to seek a waiver of the level of care requirements, the federal anti-discrimination laws likely would require the facility to seek waiver of those requirements for a resident seeking to remain in the facility.

We emphasize that this answer applies only to those situations in which a resident’s needs truly exceed what a facility can provide under the state’s level of care requirements. Sometimes a facility scapegoats state law for the facility’s refusal to admit or retain a person, even though state law actually does not prevent the facility from caring for the person.

20. *Is there merit in requiring assisted living facilities that ask a resident to leave because s/he develops needs for services that exceed the facility’s level of care standards, to help with the transfer of the resident to another setting in which higher-level services can be provided? Alternatively, could assisted living facilities be asked to assist residents if they wish to “age in place” and bring in additional services?*

In this scenario, assistance with transition to another setting is the very least that a facility should be expected to do.

We recommend that licensure or certification standards be clear as to what services must be provided by an assisted living facility, and set meaningful quality of care standards for provision of those services. As appropriate, licensing standards could offer different levels of licensure—Levels I, II, and III, for example—depending on the types of care needs that were to be accommodated. Medicaid HCBS certification standards, on the other hand, should be uniform, since by definition all Medicaid HCBS beneficiaries have care needs that would warrant nursing facility admission.

A resident's ability to remain in an assisted living facility generally should not depend on the resident bringing in additional services. Instead, the facility should have the capacity to provide necessary services or to arrange for those services. Services should be coordinated and the facility must be responsible for those services. It can be a recipe for disaster if, instead, the facility were to provide a lesser level of care, with the resident attempting to fill in gaps by arranging for supplemental services by others.

There may be times for a resident's hiring of additional caregivers, but such hiring should be kept to a minimum. In general, facility staff should be responsible for ensuring that a resident's care needs are met.

21. *Are negotiated risk agreements, as used in some states, a mechanism whereby assisted living facilities and residents (or in specified circumstances, residents' surrogates) can attempt to negotiate additional services for residents whose care needs are found to exceed state licensing levels of care?*

In a negotiated risk agreement, the resident agrees to stay in a facility even though the facility's level of care is inadequate. The agreement includes a waiver that releases the facility from liability for the inadequate care. For example, an immobile resident might agree to remain in an assisted living facility even though the facility lacks the staff to regularly reposition the resident, and in a negotiated risk agreement would release the facility from liability from any pressure sores that the resident might develop.

Negotiated risk agreements are unenforceable under consumer contract law—a consumer health care contract violates public policy if it releases the health care provider from liability. For example, a consent to surgery must not release the hospital or surgeon from responsibility for negligence. *See, e.g., Tunkl v. Regents of Univ. of California*, 383 P.2d 441 (Cal. 1963).

To this point, only one court has addressed the validity of negotiated risk agreements in assisted living. A resident's fall in an assisted living facility had caused the resident to suffer irreversible brain damage and permanent physical impairments. In its defense, the facility pointed to provisions of the admission agreement that exempted the facility from liability "for personal injuries or damage to property, even if resulting from the negligence of [the facility] or its employees." Citing this language, the facility argued that the resident had waived the facility's liability in return for having "independence, control and choice," and "a higher quality of life." *Storm v. NSL Rockland Place, LLC*, 898 A.2d 874, 878-79 (Del Super. Ct. 2005). The judge, however, emphatically rejected this argument, concluding that it would be

“unconscionable” to allow the facility to use the agreement as a defense. *Storm*, 898 A.2d at 884.

Because negotiated risk agreements violate consumer contract law, and because liability waivers are difficult to defend in public policy discussions, proponents of negotiated risk recently have been muddying the waters in their defense of negotiated risk. When defending the concept of negotiated risk, they cite examples such as a diabetic resident wishing to eat a dessert, or an unsteady resident desiring to wear high heels for a special occasion. These examples confuse matters, because they involve situations in which the facility’s level of care is irrelevant. Such examples involving diabetic residents or high heels are simply situations in which a resident is choosing to act against a facility’s recommendations. There is no need for an “agreement” in such situations; nursing homes and assisted living facilities routinely address those situations under current law by documenting that the resident is acting against medical advice.

I have written a law review article on this topic: Eric M. 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). A copy of the article is submitted along with these answers.

22. *Are there any industry recognized best practices in assisted living? If so, what are they?*

A best practice is to hire adequate numbers of direct-care staff members, and to give them training comparable at least to the training provided to certified nurse aides in nursing homes. A related best practice is to hire persons with adequate health care expertise (including but not limited to nurses) in order to meet residents’ needs and allow residents to remain living longer in an assisted living setting.

23. *What is the state role in regulating assisted living?*

States set standards, conduct inspections, investigate complaints, enforce relevant laws, and issue licenses. The specifics of a state’s actions differ greatly from state to state. Many states are relatively lax in their standard-setting and enforcement. The better states set quality of care standards that are consistent with the care needs of the persons who can be admitted as residents. The less conscientious states rely heavily on the facility’s disclosure of its care practices and/or on the terms of the admission agreements signed by residents.

24. *Recognizing that states differ across the board in their regulations, are there any particular practices that most states consider to be a deficiency as it relates to their surveys of facilities?*

Recent deficiencies cited by state agencies often reflect insufficient numbers of staff and poorly trained staff. Sometimes the deficiencies discuss quality of care problems, but the root cause is likely staffing inadequacies.

For example, North Carolina officials recently cited poorly trained staff and unsafe diabetes care as leading to six fatal cases of hepatitis B in a North Carolina assisted living facility. Over several years the state fined 42 facilities for deficiencies involving the insulin administration, often by unlicensed “med techs.” Thomas Goldsmith, *Diabetes Care Raises Alarm*, News & Observer (Dec. 26, 2010), www.newsobserver.com/2010/12/26/881880/diabetes-care-raises-alarm.html#.

25. *What constitutes a successful survey process? Please feel free to allude to examples from any State.*

A successful survey process requires a comprehensive, validated survey protocol; well-trained surveyors working in a multi-disciplinary team; unannounced annual surveys; and timely complaint investigations. To our knowledge, no state system includes all of these features. States generally do not have a formal survey protocol and do not require special training for their surveyors. We are unaware of any validation of survey protocols in the states that use specific protocols. *See Long-Term Care Community Coalition, Oversight of Assisted Living in the United States: Summaries of State Requirements and Practices* (2010).

Moreover, due to budgetary restrictions, state surveys are becoming less frequent and less comprehensive. States are increasingly relying on models of surveying that call for surveying of only certain facilities or certain aspects of a facility, depending on certain “key indicators.” Relying on such indicators has not been tested in the assisted living context, and states use these systems not because states think that these systems are the most effective, but because such systems are less expensive. We recommend against such trade-offs, and contend that a more comprehensive oversight approach is needed to protect the increasingly vulnerable population of assisted living residents. *See Webinar of Assisted Living Consumer Alliance*, Aug. 10, 2010, www.assistedlivingconsumers.org/digest.2010-07-27.6518695705.

26. *What sort of policies and resources do assisted living communities have in place to ensure quality? Are there any quality assurance policies of note that have been planned for the future?*

Ideally, an assisted living facility will provide a comprehensive training program for all of its direct-care workers. State requirements in this area can be weak—California, for example, sets a minimum of only ten hours of initial training for direct-care employees—so in most states it is critical that facilities exceed the state-set minimum. *See* Section 87441(c) of Title 22 of the California Code of Regulations.

It is similarly critical that facilities set staffing levels at an adequately high level. Most states do not set firm numerical staffing minimums, leaving to individual facilities the responsibility to determine adequate staffing levels.

Care should be coordinated through a written plan of care, and that plan should fully incorporate health care, personal care services, activities, and other aspects of the resident's life in the facility.

27. *Would you describe assisted living as a cost effective model for long-term care? Please explain why or why not?*

Assisted living is potentially a cost effective model for long-term care. It is difficult to generalize in this area, as assisted living facilities can differ greatly from one another, both from state to state and within the same state.

Assisted living care is cost effective to the extent that it allows persons to move out of nursing facilities, or delays the need for nursing facility care. On the other hand, assisted living care is not cost effective to the extent that residents could otherwise be living at home with the necessary services, and if poor quality assisted living care leads to adverse outcomes and unnecessary hospitalizations.

28. *How does customer satisfaction in assisted living communities compare with other long term care options?*

We do not know of any data that definitively answer this question. Consumer satisfaction measures for long-term care facilities can be of questionable validity, depending on the methodology. Residents often suffer from cognitive deficits and, given that residents are living under the supervision of facility staff, both residents and family members can feel pressure to answer questions in a way that would satisfy facility staff.

29. *In light of the evolution of effective and rigorous state oversight of assisted living, what would necessitate a greater federal role apart from Medicaid?*

We do not agree with this question's premise. State oversight of assisted living is not necessarily effective or rigorous. As discussed in our answer to Question #25, surveys in many states are conducted infrequently. For example, California law generally requires a state survey of an assisted living facility (called a "Residential Care Facility for the Elderly" under California law) only once every five years. *See* Section 1569.33(d) of the California Health and Safety Code.

Even when deficiencies are cited, enforcement consequences may be grossly inadequate as compared to the magnitude of the violation. For example, Florida imposed only a \$10,000 fine (reduced to \$7,500) when a 93-year old assisted living resident with advanced Alzheimer's disease died, with severe burns to his esophagus, 18 hours after he drank a sodium hydroxide solution used as dishwasher detergent. Earlier, the facility had been fined \$3,000 "related to a February 2009 incident in which at least 10 residents became sick with norovirus. An April 2009 inspection led to a \$1,500 fine after questions arose about the treatment of a resident's bed sores." Jon Burstein, *Suburban Delray Beach Assisted Living Facility Fined in Resident's Poisoning Death; Homewood Residence at Delray Beach Did Not Admit Responsibility*, *The Palm Beach Post* (Nov. 15, 2010), www.palmbeachpost.com/news/crime/suburban-delray-beach-assisted-living-facility-fined-in-1048659.html.

Also, assisted living standards are often inadequate, particularly given residents' increasingly significant care needs. In too many states, standards are based on disclosure or on the terms of a facility's admission agreement with the resident.

As the question implies, a greater federal role is justified by the significant Medicaid payment for assisted living services. Also, a greater federal role can be supported by the inadequate standards and enforcement seen in many states. Finally, the increased involvement of the Federal Trade Commission is supported by the problems seen in assisted living contracts, and in the not infrequent discrepancy in assisted living between what is promised and what is delivered.

30. *Where there is a resident who wishes to age in place and the acuity of services have increased such that the facility does not offer the services needed, is there a protocol, either by law or best practices, in place for assisted living communities to follow? Does your state grant residents any particular rights to “age in place?” What, if any, federal laws address this issue?*

Ideally, state law will specify what services must be offered by an assisted living facility. A state might have one package of required services for all assisted living facilities or, alternatively, might have a different package of required services for different assisted living licensure classifications (e.g., Assisted Living I, II, or III).

In a less desirable state licensing system, a facility is not required to provide a particular package of services, but is instead required to disclose which services will or will not be provided. As discussed in our answer to Question #1, comprehensive disclosure can be helpful to consumers, but disclosure is not a panacea or a substitute for regulatory standards. Disclosure is inadequate because consumers searching for a facility generally are not prepared to distinguish between different facilities in this way, due to consumers’ unfamiliarity with the relevant issues, and to the stress and time pressure that often accompany a search for a long-term care facility.

I am based in California, which operates under regulations that only loosely describe the minimum “basic services” offered by Residential Care Facilities for the Elderly (RCFEs, California’s term for assisted living facilities). *See* Section 87464(f) of Title 22 of the California Code of Regulations. In addition to the basic services, certain health conditions—such as diabetes and incontinence—are “restricted” and in general can be accommodated under licensure rules only if the necessary care can be provided by the resident or by an appropriately skilled professional. The regulations speak generally of what the facility “may” do, as opposed to what it “must” do, suggesting that a facility would have the option of whether or not to arrange for the necessary care for any restricted condition. *See* Sections 87609- 87631 of Title 22 of the California Code of Regulations.

Thus, California RCFE law does not give a resident a right to age in place in an RCFE: a facility is not required to provide the necessary care for a restricted health condition. Additionally, a facility but not a resident has the authority to seek waiver of a “prohibited” health condition such as a Stage III or IV pressure sore. *See* Section 87616 of Title 22 of the California Code of Regulations.

In federal law, these situations are addressed by the Americans with Disabilities Act (ADA) and the Fair Housing Amendments Act (FHAA), each of which requires facilities to offer reasonable accommodations for persons

with disabilities, as long as the reasonable accommodation does not constitute a fundamental alternation to the facility's operation, or cause an undue administrative or financial burden. As long as a state's licensing law allows a facility to provide care for a certain condition, the facility under the ADA is required to provide the necessary care as a reasonable accommodation that would not be a fundamental alteration, and likely would not cause an undue burden. The assisted living law in the State of Washington explicitly incorporates the ADA's reasonable accommodation requirements, but the ADA and the FHAA apply with equal force in any state, whether or not the state's assisted living law mentions them. *See* Wash. Rev. Code Ann. §§ 18.20.310(2), 18.20.320(1), 18.20.330(1).

31. *As many know, there are ways to creatively qualify for Medicaid where one ordinarily would not (i.e. estate planning to hide income and assets.) With that in mind, are there any State laws and/or best practices in the assisted living industry to protect against any instances of such fraud?*

Particularly after changes made by the 2005 Deficit Reduction Act, federal Medicaid law has strong provisions that do not allow persons to hide income or assets. A Medicaid applicant for nursing facility care or HCBS waiver services is penalized for any give-away made within five years prior to the date of application. The penalty is a period of ineligibility for the number of months for which the transferred-away money could have paid for the relevant services.

As a result, there is no incentive to give away money. If (for example) a person were to give \$20,000 away, he or she would incur \$20,000 of private-pay charges in the facility during ineligibility.

Furthermore, Medicaid programs in some states are following procedures that make a person ineligible forever for HCBS waiver services after transfer of even a small amount of money. In these states, the period of ineligibility is deemed to run only after the person is admitted to a nursing facility. So for an assisted living resident, the penalty period will never begin running, and will last forever.

Recently, a federal district court in New Jersey ruled that the New Jersey Medicaid program violated federal law in imposing the never-ending penalty. *See Frugard v. Velez*, 2010 WL 1462944, 2010 U.S. Dist. LEXIS 34996 (D. N.J. Apr. 8, 2010). This court ruling, however, explicitly addressed only the individual plaintiffs, and state Medicaid programs are still imposing never-ending penalties on person seeking waiver coverage. *See, e.g.,* Arkansas Dep't

of Health & Human Servs., Division of County Operations, Policy Directive, Medical Services Policy Manual, MS 06-09.

The National Senior Citizens Law Center recently published a policy issue brief on this issue, entitled *Transfer of Assets: Making Assisted Living Residents Ineligible Forever*. A copy of this white paper is submitted with these answers.

32. *Presuming that they would be in a position to do so, should assisted living providers have a duty to help the State identify instances of Medicaid eligibility fraud? If so, please explain.*

It would not be appropriate to impose on assisted living providers a duty to help the State identify instances of Medicaid eligibility fraud. Determination of Medicaid eligibility can be a complex process. Detailed rules govern when particular income or resources are counted or excluded, and determine whether and to what degree an at-home spouse will be entitled to an allocation of income or resources from the spouse in the assisted living facility. Providers are not in a position to judge these rules' applicability to residents, and should not be expected to do so.

Privacy and personal autonomy should be a hallmark of assisted living care. Placing "identification" duties on facilities would run contrary to those principles, and could be interpreted by facilities as an invitation or requirement to scrutinize residents' personal affairs. Also, such duties would constitute discrimination against Medicaid-eligible residents. As discussed in question and answer #17, Medicaid-eligible residents already face discrimination from providers. A provider could use an "identification" duty as a lever against less desirable residents. Residents and their families are vulnerable to unjustified claims that they have run afoul of Medicaid's program complexities and could easily be frightened into accepting an unjustified discharge rather than risking loss of Medicaid eligibility.

33. *Are there ways to streamline federal programs to reduce barriers to public assistance for low-income senior housing projects? How are any of the relevant federal agencies working to achieve this? If none are, please describe some ways in which they could.*

Application cycles for the various programs should be coordinated so that the various types of funding (federal, state, local) can be lined up at the same time. Similarly, funding for housing and services also should run on the same or similar cycles.

HUD has proposed legislative reforms to the Section 202 and Section 811 programs to provide supportive housing for the elderly and to people with disabilities. Information regarding those proposals is available at www.hud.gov/offices/hsg/mfh/202811/sec202reform.cfm (Section 202) and www.hud.gov/offices/hsg/mfh/202811/sec811reform.cfm (Section 811).

34. *[no answer submitted]*

35. *[no answer submitted]*

36. *[no answer submitted]*

37. *[no answer submitted]*

38. *[no answer submitted]*

39. *[no answer submitted]*

40. *[no answer submitted]*