Home and Community-Based Services Settings Rule:
Ensuring Individual Choice and Privacy

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The federal Center for Medicaid and Medicare Services (CMS) promulgated regulations in 2014 which established standards for the settings in which Medicaid-reimbursed home and community-based services (HCBS) may be provided (42 C.F.R. § 441.301). These regulations also pertain to the settings in which individuals who receive HCBS may reside, even if the Medicaid HCBS are provided in a different setting. ***The federal regulations focus on community integration, individual choice and privacy, and other factors that relate to an individual's experience of the setting as being home-like and not institution-like.*** These regulations set a floor for Medicaid reimbursement, but states may elect to set more stringent requirements. States have been charged with developing a transition plan to ensure that state Medicaid programs come into compliance with the new HCBS expectations by March 2022. As of November 2017, seven states (Arkansas, Delaware, Kentucky, Oklahoma, Tennessee, Washington, and the District of Columbia) have received final CMS approval of their Transition Plans.

CMS outlines requirements to ensure resident choice and privacy, and allows for modifications through the person-centered planning process.

Individual choice and privacy are among the most crucial elements regarding settings of care under the HCBS rule.

Home and community-based settings must have the following qualities based on the needs of the individual as indicated in their person-centered plan:
The setting is selected by the individual from among setting options including an option for a private unit in residential setting;

- Ensures an individual's rights of privacy, dignity, and respect, and freedom from coercion and restraint;
- Optimizes, but does not regiment individual initiative, autonomy, and independence; and
- Facilitates individual choice regarding services and supports, and who provides them (42 CFR 441.301(c)(4))

Provider-owned and -controlled residential settings have additional requirements. These include that residents have:

- Freedom and support to control their own schedules activities, and have access to food at any time;
- Privacy in their sleeping or living unit; and
- Visitors at any time. (42 CFR 441.301(c)(4)(vi))

Unit Requirements:

- Units have entrance doors that individuals can lock
- Individuals sharing units have choice of roommates
- Individuals have freedom to furnish or decorate

The rule allows modifications of these additional requirements through the person-centered planning process.
Modifications must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented:

1. Identify a specific and individualized assessed need;
2. Document the positive interventions and supports used prior to any modifications to the person-centered service plan;
3. Document less intrusive methods of meeting the need that have been tried but did not work;
4. Include a clear description of the condition that is directly proportionate to the specific assessed need;
5. Include regular collection and review of data to measure the ongoing effectiveness of the modification;
6. Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated;
7. Include the informed consent of the individual; and
8. Include an assurance that interventions and supports will cause no harm to the individual (42 CFR 441.301(c)(4)(vi)(F))

The regulations acknowledge that informed consent is, for some individuals, appropriately handled by authorized representatives.

CMS guidance and state examples provide examples of demonstrating and documenting resident choice and privacy.

In Exploratory Questions to Assist States in Assessment of Residential Settings, CMS includes examples of assessment questions that provide some insight into possible compliance strategies for assisted living communities (AL communities).

- **Roommates**
  - Key questions during assessment: Was the individual given a choice of a roommate? Do married couples share or not share a room by choice? Does the individual know he/she can request a roommate change? [1] (Note: CMS has clarified that accommodating an individual's preference for a private room is not the obligation of every residential provider, but rather should be addressed as part of the state's person-centered planning process; factors such as an individual's ability to afford a private room may be considered.)
  - Possible supporting documentation: AL community policies show how and when individuals are made aware of the process to request a roommate change.
- **Food**
  - Key questions during assessment: Does the individual have a meal at the time and place of his/her choosing? Can the individual request an alternative meal if desired? Are snacks available any time? Is the individual required to sit at an assigned seat? If an individual wants to eat privately, can he or she do so? [2]
  - Possible supporting documentation: AL community policies show that individuals can eat privately, do not have assigned seats, can eat when or where they choose. If there are set meal times, policies describe how individuals may access snacks and other food when desired.

[1] Exploratory Questions to Assist States in Assessment of Residential Settings, pg. 1 https://www.medicaid.gov/medicaid/hcbs/downloads/exploratory-questions-re-settings-characteristics.pdf, accessed 11/29/2017

- **Privacy**
  - Key questions during assessment: Does the individual have a private cell phone, computer or other personal communication device or have access to a telephone or other technology? Do individuals' rooms have a telephone jack, Wi-Fi or ethernet jack? Are schedules of individuals for PT, OT, medications, or restricted diets posted in a general open area for all to view? [3]
  - Possible supporting documentation: AL community policies show that individuals have access to private communications, assure personal and medical information is protected, and document that residents' units have entrance doors that can be locked and bathroom privacy is ensured.
- **Choice**
  - Key questions during assessment: Do staff ask the individual about her/his needs and preferences? Does the individual know how and to whom to make a request for a new provider? How is it made clear that the individual is not required to adhere to a set schedule? Does the individual have access to such things as a television, radio, and leisure activities that interest him/her and can s/he schedule such activities at his/her convenience? [4] (Note: Federal guidance has clarified that if a person chooses, through an informed person-centered planning process, to live in an AL community, s/he is choosing the AL community to be the provider of assisted living services as well.)
  - Possible supporting documentation:
    - AL community policies describe the areas of resident choice and control and how these are supported through, for example, staff training, resident communications, etc.
    - AL community policies show that visiting hours and visiting areas are not restricted or, if there are visiting hours, they allow for flexibility.

CMS guidance is clear that modifications to any of the additional requirements for provider-owned or -controlled residential settings must cause no harm and must be highly individualized, based on a specific assessed need, documented in the person-centered plan, reviewed periodically, pursued only when less restrictive efforts have failed, and implemented in accordance with the regulations.

Individual choice and privacy, along with related restrictions, must be documented in the person-centered plan.

States are expected to facilitate consumer choice regarding who provides services under the plan (such as the choice of assisted living or other service options). This includes any consideration of options for private rooms, as well as options that are not disability-specific settings. These choices should be documented in the person-centered plan.

Other elements of documentation relating to privacy and choice are the responsibility of the provider. AL communities can consider use of resident or tenant agreements that incorporate the federally required assurances; documentation of staff training, qualifications and expectations; offering residents the opportunity to provide anonymous feedback through valid consumer experience surveys and/or other mechanisms; using residents' councils, committees or advisories to review aspects of policy, procedure, and practice related to privacy, choice and control; assuring that policies incorporate the person-centered modification process as outlined in the rule; and avoiding "house rules" that restrict personal freedoms for residents as a whole.

[2] Ibid., pg. 2.
[3] Ibid., pg. 3.
[4] Ibid., pg. 2-3.

Person-centered care plans for individuals living in provider-owned or -controlled residential settings also need to carefully document any restrictions that may be required regarding privacy and choice in these settings.

AL communities should ensure that:

- The policies and procedures of the AL community align with the requirements of the rule, using guidance from CMS as well as the examples listed above.
- If an individual needs a modification to the provider-owned or -controlled residential settings requirements, the need is assessed and documented in the person-centered plan, as specified in the rule.
- If an individual has chosen a setting with controlled-egress, the person-centered plan should document the choice, including the other settings considered (e.g., did the planning process consider in-home options?). Settings with controlled egress must document each resident's need for the intervention (as well as provide ways for residents without the need for restriction to come and go).
- Individuals with advanced dementia or other conditions may no longer be able to respond to questions or communicate in words, including to demonstrate their choices or consent. The person-centered planning process must still involve them to the maximum extent possible and reflect their preferences, and may necessarily include the authorized representative as decision-maker. Strategies include:
    - Learning and documenting an individual's personal history and past routines, including through input from family and friends.
    - Recognizing and documenting behavior as a form of communication, and interpreting that behavior from the individual's point of view. and
    - Documenting when decisions are made by the individual, and when they are made by the individual's designated representative.[5]

Some state policies and practices have created challenges for AL communities with regards to care planning. For example, many states require a separate service plan be developed by the AL community, but in some states, the AL community care plan is not informed by the person-centered planning process conducted by the HCBS care manager (e.g., some states may currently exclude the AL community provider from the person-centered planning process or not share the person-centered plan with the AL community). Some states may also defer some care planning responsibilities to the AL community. In these situations, AL community providers should seek clarity from states on the expectations for AL community provider roles in person-centered planning, and ensure that providers understand and, where appropriate, are involved in the essential elements of compliance, including documentation and data collection.

State compliance strategies generally recognize and accommodate variations in how providers achieve a home and community-based experience of care for residents.

In doing so, states stay true to the goal of assuring that consumers can choose among participating non-institutional settings of care, including AL communities, based on individual preferences for how the services and supports necessary for community living are delivered.

[5] Center for Excellence in Assisted Living (CEAL) comments submitted to the Centers for Medicare and Medicaid Services (CMS) on guidance implementing the HCBS Final Rule: person-centered dementia care in assisted living, June 29, 2016, http://www.theceal.org/images/Documents/CEAL-comments-to-CMS-6-29-16.pdf, accessed December 12, 2017.

States' approaches to ensuring choice and privacy are often revealed in the tools they use for provider self-assessments, on-site reviews, understanding consumer experience, and heightened scrutiny analysis. These tools also provide a specificity that AL communities can use in developing concrete strategies to revise policies, programs or practices and to demonstrate compliance with the rule.

Although Oklahoma found several AL communities out of compliance for reasons related to privacy and community, for one AL community the state considered the following policies to be compliant with the HCBS settings standards:[6]

- The AL community serves residents receiving Medicaid HCBS and those paying through other means, and ensured a similar experience and community access for all residents.
- While the dining room has meal times, small meals and snacks are available at any time. Residents are also provided a microwave, refrigerator, and storage space for utensils in each unit. A private dining room is available, as is the option to eat in a resident's room.
- The AL community has no Wi-Fi or ethernet, but public phones are available, with phone jacks in each room.
- Visitors are requested to leave by 8pm, but may stay longer if not disturbing other residents. Overnight guests are allowed on limited time basis.

The Arkansas site review tool provides greater specificity on requirements for choice and privacy.[7] These provide concrete examples that on-site review staff can observe, including:

- May the resident lock the bathroom door for privacy? (Delaware also included this requirement for AL communities).
- Does the staff knock on the door/ring a doorbell for access to the resident's private room(s)?
- Is the setting arranged to ensure privacy during personal care?
- Can beneficiaries choose to do their own laundry in this setting?

Tennessee instituted a compliance oversight process that included documentation review. It considered whether the vision and mission of the agency includes evidence of community access, whether promotional material mentions community integration, and whether the agency policies, procedures, and staff training align with the rule.[8] The District of Columbia's provider self-assessment tool largely matches the CMS guidance, but adds a question about ensuring that visitors are not restricted to only designated areas.[9]

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[6] Oklahoma Statewide Transition Plan, Submission for Final Approval, January 2017, pg. 126-128 https://www.okhca.org/individuals.aspx?id=16904, accessed 11/29/2017

[7] Arkansas Department of Human Services, Home and Community-Based Services (HCBS) Statewide Settings Transition Plan, pg. 160-181, https://www.medicaid.gov/medicaid/hcbs/downloads/ar/ar-approved-plan.pdf, accessed 11/29/2017.

[8] Tennessee Division of Health Care Finance and Administration, Element #2 Heightened Scrutiny Documentation Assessment Tool, https://tn.gov/assets/entities/tenncare/attachments/HeightenedScrutinyDocumentationAssessmentTool.pdf, accessed 11/29/2017.

[9] The Government of the District of Columbia Department of Health Care Finance, HCBS Settings for Assisted Living and Community Residence Facilities, pg. 3 https://dhcf.dc.gov/sites/default/files/dc/sites/fems/publication/attachments/Settings%20Provider%20Self-Assessment%20Tool%202%2019%2016%20%282%29.pdf, accessed 11/29/2017.