

Home and Community-Based Services Settings Rule: An Effective Person-Centered Planning Process Is Key for Memory Care Units

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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.

Memory care is an alternative setting to nursing facility care for individuals with dementia.

Many assisted living (AL) communities created memory care units as an alternative to nursing facility care for individuals with dementia who need supervision as well as hands-on assistance with activities of daily living or instrumental activities of daily living. Memory care units may also offer programming specifically designed to support individuals who are struggling with dementia. Often, these units are physically separated from other parts of the AL community and may have a separately secured entrance that is intended to prevent individuals who are confused from unsafe wandering or eloping.

The regulatory language from CMS creates requirements that may be challenging for AL communities that offer memory care units.

The Medicaid HCBS regulations require that, for an AL community to qualify as a setting for Medicaid-reimbursed HCBS, the setting of care must be integrated in and support full access to the community. This includes resident opportunities to:

- Engage in community life
- Control personal resources
- Receive services in the community

The setting must:

- Ensure an individual's rights of privacy, dignity and respect
- Ensure freedom from coercion and restraint
- Optimize individual initiative, autonomy and independence in making life choices, including in daily activities and physical environment and with whom to interact.

The regulations include additional requirements for provider-owned or -controlled settings. These include provisions that may create a challenge for memory care units, such as, "Each individual has privacy in their sleeping or living unit, units have entrance doors lockable by the individual, with only appropriate staff having keys to doors..." and "Individuals have the freedom and support to control their own schedules and activities..." (42 CFR § 441.301(c)(4)(v)). In evaluating residential settings, CMS guidance encourages states to identify whether a setting uses "gates, Velcro strips, locked doors, or other barriers preventing individuals' entrance to or exit from certain areas" or whether individuals can come at will.¹

An effective person-centered planning process—where any restrictions are consistent with an individual's health and safety needs—will support a finding that the memory care unit is an alternative setting that emphasizes choice, dignity, and respect.

The HCBS regulations acknowledge that individuals may have conditions or needs that require some modification to the additional requirements placed on provider-controlled settings. For example, some medical conditions may require carefully controlled access to food, or some individuals with dementia may need some protection against the dangers of exit-seeking behavior.

In December of 2016, CMS issued FAQs on beneficiaries who exhibit unsafe wandering or exit-seeking behavior. A key take-away is that any interventions that may reduce privacy, limit choice, restrict freedoms, use physical restraint or otherwise seemingly violate the characteristics of a HCBS setting may be allowable if the modification is: implemented on an individual basis after trying less restrictive approaches; consistent with individual assessed health and safety needs; and reviewed regularly, documented appropriately, and causes no harm.

The regulations require that any modifications must be supported by a specific assessed need and justified in the person-centered service plan. **The following requirements must be documented in the person-centered service plan:**

- A specific and individualized assessed need;
- The positive interventions and supports used prior to any modifications to the person-centered service plan;
- Less intrusive methods of meeting the need that have been tried but did not work;
- A clear description of the condition that is directly proportionate to the specific assessed need;
- Regular collection and review of data to measure the ongoing effectiveness of the modification;
- Established time limits for periodic reviews to determine if the modification is still necessary or can be terminated;
- The informed consent of the individual; and
- An assurance that interventions and supports will cause no harm to the individual.

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

An entire setting can have controlled egress, so long as the modification is documented in each resident’s person-centered plan and is consistent with each resident’s current individual assessed needs.

CMS guidance makes clear that individuals can, through the Medicaid person-centered planning process, choose a disability-specific setting so long as the person-centered planning process includes consideration of non-disability specific setting options. (e.g., in-home, adult day, or other services were considered).²

If an AL community has settings with controlled egress, the setting must have mechanisms so that those who do not need the modification do not have their entrance and exit controlled. CMS provides the example of a key code that allows spouses or partners who reside in the same setting and who do not have exit-seeking behavior to come and go.³ CMS guidance does not support restrictions that are automatically applied based on diagnosis or setting, nor those applied to a class or group of individuals. HCBS providers are encouraged to consider implementing promising practices regarding training for staff, environmental design, and resident activities to better serve residents who may be at risk of unsafe wandering or exit-seeking.⁴

States seeking compliance for memory care settings have largely followed the path outlined in the CMS guidance.

No state has been approved for a diagnosis-based exemption, nor for any exemption of a category or type of provider settings, from the federal HCBS settings requirements.

Washington updated its state code regarding the state’s Secure Dementia Units (WAC 388-78A-2380). The code now requires:

- Consent of the individual to live in that setting (documented in the person-centered plan).
- Systems to accommodate visitors, staff, and residents who do not need controlled egress.

Arkansas’ existing administrative code requires that keys, codes, or other opening devices be supplied to all residents without a credible diagnosis of dementia.⁵ To address this potential conflict with the rule, Arkansas updated the assisted living provider manual to include the language from the rule, that all residents must have lockable doors on their units, with only appropriate staff having keys to doors, unless modified through the person-centered planning process.

² FAQs concerning Medicaid Beneficiaries in Home and Community-Based Settings who Exhibit Unsafe Wandering or Exit-Seeking Behavior, December 15, 2016, <https://www.medicaid.gov/federal-policy-guidance/downloads/faq121516.pdf>, accessed 11/29/2017

³ FAQs concerning Medicaid Beneficiaries in Home and Community-Based Settings who Exhibit Unsafe Wandering or Exit-Seeking Behavior, December 15, 2016, pg. 4-5 <https://www.medicaid.gov/federal-policy-guidance/downloads/faq121516.pdf>, accessed 11/29/2017

⁴ Questions and Answers Regarding Home and Community-Based Settings: Planned Construction of Presumed Institutional Settings, pg. 4-5 <https://www.medicaid.gov/medicaid/hcbs/downloads/faq-planned-construction.pdf>, accessed 11/29/2017

⁵ Arkansas Department of Human Services, Home and Community-Based Services (HCBS) Statewide Settings Transition Plan, pg. 72, <https://www.medicaid.gov/medicaid/hcbs/downloads/ar/ar-approved-plan.pdf>, accessed 11/29/2017.

States and providers must work together to address challenges related to care plans.

Many states require a separate service plan be developed by the AL community, but in some of these states, the AL community care plan is not being 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 policies under the new regulations should stay true to the goal of ensuring 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.

State policy should be clear in how the person-centered planning process will address and document any needed modifications to the HCBS settings requirements for an individual residing in a provider-controlled setting and how it will document, when necessary, that non-disability specific settings were considered as part of the person-centered planning process. If state policy lacks clarity, AL communities should make efforts to adopt reasonable internal documentation, using federal guidance, including for any necessary modifications to the regulatory requirements for provider-operated residential settings.

In a memory-care setting with controlled egress, AL communities and the HCBS case manager should collaborate to ensure that the person-centered plan documents the individual's:

- Understanding of the setting's safety features, including controlled egress.
- Choices for prevention of unsafe wandering or exit seeking.
- Consent from the individual to controlled egress as part of the person's goals and needs.
- Services, supports, and environmental design that support the individual's mobility and ability to participate in activities.
- Options explored other than controlled egress.
- Continuing need for controlled egress based upon periodic data collection and review.

Adopting or adapting best and promising practices from dementia literature can help memory care providers meet both the spirit and letter of the rule.

The demand for care options for individuals with dementia will continue to grow with the aging of state populations. Organizations including the Center for Excellence in Assisted Living (CEAL),⁶ the Alzheimer's Association,⁷ the CCAL,⁸ and the federal Administration for Community Living (ACL)⁹ are among groups publishing information that share promising practices and approaches that can support improved quality of life for this population.¹⁰

The Alzheimer's Association describes three key elements of dementia care practice. These include:

- Food and fluid consumption – including proper nutrition and hydration, and nutrition care. Person-centered practices will also promote good nutrition through culturally appropriate meals and enjoyable and flexible meal times and snacks.
- Pain management – including avoiding over-utilization of psychotropic medications, treating pain as a vital sign, and tailoring pain management to the individual. Person-centered practices take into account an individual's behavior as an indication of potential pain.
- Social engagement – including opportunities for fun, community, and meaningful interactions. Person-centered practices will respect individual preferences, including preferences to be alone, and an individual's history or role in their communities.

The ACL and CEAL have documented person-centered strategies that may improve person-centered planning and service delivery for people unable to express their preferences using words. These include:

- Recognizing and documenting behavior as a form of communication, and interpreting that behavior/communication from the individual's viewpoint.
- Learning an individual's personal history and communicating this information to relevant staff interpret behavior or other communication.
- Relating to each resident as an individual; personalizing the individual's care and surroundings.
- Involvement of the individual in decision-making to the maximum extent possible.
- Incorporating input of family and friends to inform their preferences and choices.
- Ensuring that the individual-caregiver relationship is as important as the care tasks.

⁶ 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.

⁷ Alzheimer's Association, Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes, https://www.alz.org/national/documents/brochure_DCPRphasesIn2.pdf, accessed December 15, 2017

⁸ CCAL, Dementia Care: The Quality Chasm, <http://www.ccal.org/national-dementia-initiative/white-paper/>, accessed December 15, 2017

⁹ Tilly, Jane, Responding to the Wandering and Exit-Seeking Behaviors of People with Dementia, Center for Policy and Evaluation, Administration for Community Living, May 2015, <https://www.acl.gov/sites/default/files/triage/BH-Brief-WanderingExit-Seeking.pdf>, accessed December 12, 2017.

¹⁰ Resources for Integrated Care, Medicare-Medicaid Coordination Office, Managing Behaviors Associated with Dementia: Resource Guides, https://resourcesforintegratedcare.com/GeriatricCompetentCare/2017_GCC_Resource_Guides/Dementia, accessed January 24, 2018.

The ACL and CEAL have also published strategies and best practices for person-centered responses to exit-seeking. While wandering or exit-seeking can often be dangerous, it also may have a purpose. People may wander out of distress, in response to a noisy or confusing environment, or out of response to a basic human need like hunger or thirst. Person-centered interventions can assist providers to prevent or limit this behavior, as well as allow it in safe ways. Strategies include:

- Documenting patterns, frequency, and triggers of exit-seeking behavior, then using this information to develop a person-centered plan that limits triggers of unsafe wandering and periodically re-assessing the success of these interventions.
- Learning an individual's personal history, past routines, and background to help interpreting behavior and inform what they may be seeking.
- Using environmental design to address common causes of unsafe wandering, such as avoiding over- or under-stimulation; providing safe, uncluttered paths to points of interest; and using signage to orient individuals to the environment. As one example, Washington State regulations (WAC 388-78A-2380) require a secure outdoor space attached to Secure Dementia Units that residents can access without staff assistance, is protected from direct sunshine and rain, has firm walking surfaces, and has suitable outdoor furniture.
- Training staff in dementia, person-centered planning, and safe handling of behavioral expressions of need or distress.

Each of these strategies can be documented in an AL community's policies and procedures, as well as individual person-centered plans. Delivery of care in a person-centered manner is crucial for individuals living with dementia, and the importance of a person-centered approach increases as their disease advances.