
FAQs concerning Medicaid Beneficiaries in Home and Community-Based Settings who Exhibit Unsafe Wandering or Exit-Seeking Behavior

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The regulation issued by the Centers for Medicare & Medicaid Services (CMS) on January 16, 2014¹ finalized the criteria for home and community-based settings for the purposes of Medicaid funding. Applying to services authorized under 1915(c) home and community-based services (HCBS) waivers, and 1915(i) HCBS and 1915(k) Community First Choice state plan options, the criteria require settings receiving HCBS funding to facilitate beneficiary independence and decision-making in defining desired integration into their communities. As states, providers, beneficiaries and other stakeholders determine a strategy for complying with the setting requirements during a transition period that ends March 17, 2019, questions have arisen on how to adhere to the individualized nature of service provision for individuals with dementia or other conditions in which unsafe wandering or exit-seeking behavior is exhibited. The following guidance begins with an articulation of how regulatory requirements can be met by settings providing HCBS to individuals with such behavior, and concludes with describing some options for HCBS stakeholder education and consideration.

Q1: How can residential and adult day settings comply with the HCBS settings requirements while serving Medicaid beneficiaries who may wander or exit-seek unsafely?

A1: Many Medicaid beneficiaries living with dementia and other conditions can have a heightened risk of wandering, or attempting to leave a setting (exit-seeking) unsafely. These behaviors are not necessarily constant or permanent.

Wandering occurs in ways that may appear aimless but often have purpose. People may wander simply because they want to move. Sometimes wandering responds to an unmet basic need like human contact, hunger, or thirst; a noisy or confusing environment; or because people are experiencing some type of distress, like pain or the need to use the toilet. Wandering can be helpful or dangerous, depending on the situation. Although people who wander may gain social contact, exercise, and stimulation, they can also become lost or exhausted.²

Person-centered planning, staff training and care delivery are core components of provider operations to meet HCBS requirements while responding to unsafe wandering and exit-seeking behavior in an individualized manner.³ Person-centered services involve knowing individuals, and their conditions, needs, and history and using this knowledge to create strategies to assure that individuals are free to interact with others and the community in the most integrated way possible and still prevent injury for those who wander or exit-seek unsafely. Home and

¹ <https://www.gpo.gov/fdsys/pkg/FR-2014-01-16/pdf/2014-00487.pdf>

² Tilly, J., & Reed, P., (2009) Dementia Care Practice Recommendations for Assisted Living and Nursing Homes, Phases 1 & 2. Alzheimer's Association.

³ Required and defined in regulation for 1915(c) at 42 CFR §441.301(c)(1), for 1915(i) at 42 CFR §441.725, and for 1915(k) at 42 CFR §441.540

community-based settings must demonstrate that person-centered planning drives their operations and services for each person. The beneficiaries the settings serve must drive the person-centered planning process with assistance from a trained, competent, assessor, care manager or similar facilitator. The beneficiary should be able to get input from people who are important to him or her, while still reflecting the individual's input as much as possible. Person-centered plans and related decisions should be consistent with the person's needs and preferences, and informed by family members, caregivers, and other individuals that the beneficiary has identified as playing an important role in his or her life. The role of person-centered planning and the process for realizing this role is described in the final HCBS regulation and in guidance found on the Medicaid.gov website.

Person-centered service plans should be developed with the individual, and include their representatives as appropriate. The person-centered planning process should include a process that:

- is informed by discussions with family members or other individuals who are important to them about key aspects of daily routines and rituals;
- focuses on an individual's strengths and interests;
- outlines the individual's reaction to various communication styles;
- identifies the individual's favorite things to do and experience during the day, as well as experiences that contribute to a bad day;
- proposes experiences that the person may enjoy as community engagement, and describes those factors or characteristics that the individuals would find most isolating or stigmatizing.

To promote effective communication, which is at the core of person-centered planning and service delivery, provider staff serving beneficiaries who wander or exit-seek should receive education and training about how to communicate with individuals living with conditions that may lead to unsafe wandering or exit-seeking. Training programs may include important information on issues such as:

- The most common types of conditions, diseases and disorders that lead to wandering behavior; the various stages of key conditions that result in increased risk of wandering and what to expect over time; and the potential impact of these conditions on the individual's ability to function.
- Differentiating between most common types of conditions, diseases and disorders that lead to wandering behavior from serious mental illness or adverse environmental conditions such as overmedication or neglect.
- Assessing individuals for co-occurring conditions (including barriers to sufficient adaptive skills and the ability to communicate with others) that increase risk for unsafe wandering or exit-seeking.
- Understanding situations that led to past instances of unsafe wandering or exit-seeking or the desire to engage in them;
- Principles of person-centered care planning and service delivery;
- Strategies for identifying and handling behavioral expressions of need or distress.

In addition to previous guidance provided by CMS on the implementation of person-centered planning requirements outlined in the federal HCBS regulations defining home and community-

based settings, integration of the following promising practices around person-centered planning specifically for people who wander or exit-seek unsafely is recommended:

- Assessing the patterns, frequency, and triggers for unsafe wandering or exit-seeking through direct observation and by talking with the person exhibiting such behaviors, and, when appropriate, their families.
- Using this baseline information to develop a person-centered plan to address unsafe wandering or exit-seeking, implementing the plan, and measuring its impact.
- Using periodic assessments to update information about an individual's unsafe wandering or exit-seeking, and adjust the person-centered plan as necessary.

Q2: Can provider-controlled settings with Memory Care Units with controlled-egress comply with the new Medicaid HCBS settings rule? If so, what are the requirements for such settings?

A2: Yes, but only if controlled-egress is addressed as a modification of the rules defining home and community-based settings, with the state ensuring that the provider complies with the requirements of 42 C.F.R. 441.301(c)(4)(F), 441.530(a)(vi)(F) and 441.710(a)(vi)(F). Any setting using controlled-egress should assess an individual that exhibits wandering (and the underlying conditions, diseases or disorders) and document the individual's choices about and need for safety measures in his or her person-centered care plan. The plan should document the individual's preferences and opportunities for engagement within the setting's community and within the broader community.

Settings with controlled-egress should be able to demonstrate how they can make individual determinations of unsafe exit-seeking risk and make individual accommodations for those who are not at risk. Should a person choose a setting with controlled-egress, the setting must develop person-centered care plans that honor autonomy as well as minimize safety risks for each person, consistent with his or her plan goals. For example, spouses or partners who are not at risk for exit-seeking and who reside in the same setting should have the ability to come and go by having the code to an electronically controlled exit. Technological solutions, such as unobtrusive electronic pendants that alert staff when an individual is exiting, may be used for those at risk, but may not be necessary for others who have not shown a risk of unsafe exit-seeking. Importantly, such restrictions may not be developed or used for non-person-centered purposes, such as punishment or staff convenience.

In situations where a setting uses controlled-egress on an individual basis to support individuals who wander or exit-seek unsafely, consistent with our regulations, the person-centered plan must document the individual's:

- Understanding of the setting's safety features, including any controlled-egress,
- Choices for prevention of unsafe wandering or exit-seeking
- Consent from the individual and caregivers/representatives to controlled-egress goals for care
- Services, supports, and environmental design that will enable the individual to participate in desired activities and support their mobility
- Options that were explored before any modifications occurred to the person-centered plan

Regulations require the person-centered plan to be reviewed at least annually with the Medicaid beneficiary and his or her representative, to determine whether it needs revision⁴. If a secured memory unit is no longer necessary to meet the individual's needs, the individual must be afforded the appropriate services in that setting to integrate into the community and exercise greater autonomy as well as being offered the option of a setting that does not have controlled egress.

To assure fidelity in complying with the regulations defining home and community-based settings, Memory Care Units should attempt to implement as many options as possible that are outlined within this guidance regarding staffing, activities and environmental design to assure optimal community integration for HCBS beneficiaries.

Note that the regulations provide that Medicaid beneficiaries receiving services in home and community-based settings must be free from coercion and restraint. Consistent with this, home and community-based settings should not restrict a participant within a setting, unless such restriction is documented in the person-centered plan, all less restrictive interventions have been exhausted, and such restriction is reassessed over time.

Q3: What are some promising practices that HCBS settings use to serve people who are at risk of unsafe wandering or exit-seeking?

A3: Person-centered planning is at the core of all promising practices. That said, there are staff, activity, and environmental design approaches, as described below, which could be part of an individual's person-centered plan in response to unsafe wandering and exit-seeking. These promising practices have been compiled from industry and governmental sources⁵ and are offered as suggestions as they do not constitute requirements for HCBS services or providers.

Staffing:

- Ensure that staff have adequate training in person-centered planning and unsafe wandering or exit-seeking, including how to effectively engage and participate with individuals in both planned and spontaneous activities as well as strategies for addressing the underlying needs and preferences that may motivate wandering or exit seeking.
- Support individuals to move about freely with staff who help individuals walk or leave the room safely (e.g., providing a walking companion).
- Ensure adequate staffing for activities outside the facility.
- Ensure staff regularly escorts individuals to locations and activities outside of the setting as outlined in the person-centered services plan.

⁴42 CFR 441.301(c)(3) for 1915(c); 42 CFR 441.725(c) for 1915(i); and 42 CFR 441.540(c) for 1915(k).

⁵ See the Alzheimer's Association's Dementia Care Practice Recommendations at http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp, an issue brief from the Administration for Community Living titled "Responding to the Wandering Behavior of People with Dementia" in the Dementia section at http://www.acl.gov/Get_Help/BrainHealth/Index.aspx, and the Center on Excellence in Assisted Living guidance on this topic at <http://www.theceal.org/>

- Provide flexible supervision to assure adequate support from resident to resident and from time to time for the same resident dependent upon need.

Activities:

- Prevent under-stimulation by offering activities that engage the beneficiary's interest. Activities could include music, art, physical exercise, mental stimulation, therapeutic touch, pets, or gardening.
- Provide a wellness program to help people exercise, have a healthy diet, manage stress, improve balance and gait, and stimulate cognition.
- Support mobility through engaging activities, such as dog walking, gardening, yoga, and dance.
- Develop daily meaningful activities and minimize passive entertainment, such as television watching.
- Make available easily accessible activities, such as playing cards, reading books and magazines.
- Encourage interaction with others.
- Ensure that family and friends have unrestricted access to the individual if she or he wants this, and to the setting itself.

Environmental design:

- Eliminate overstimulation, such as visible doors that people use frequently; noise; and clutter.
- Create pictures on walls that can be sensory in nature to give individuals a place to stop and experience through sight or touch.
- Manage shift changes so that individuals do not see significant numbers of staff coming and going through the exit/entrance door at the same time.
- Use signage to orient the individual to the environment, such as indicating where toilets and bedrooms are, and assuring that there are places for individuals to sit and rest in large spaces within a setting that allow for safe wandering.
- Disguise exit doors using murals or covering door handles as safety codes permit.
- Use unobtrusive technological solutions, such as installing electronic coding lock systems on all building exits, or having individuals who wander or exit-seek unsafely wear electronic accessories that monitor their location.
- Include lockable doors on each individual's room unless the resident's person-centered plan documents that such an arrangement is unsafe, following the requirements of the rule on individual modifications. Alternative features designed for safety, such as doors on living units that are not lockable or secure exits, should be used only when they are part of the resident's person-centered plan, after less intrusive methods have been tried and did not work, as provided in the rule.
- Ensure unrestricted access to secured outdoor spaces and a safe, uncluttered path for people to wander, which has points of interest and places to rest.
- Identify quiet, public spaces for individuals to sit, observe and rest while simultaneously being part of the community, and may include items that are used to soften the senses or help with removing sensory stimulation.

- Enable people to leave the premises when they are not at risk of doing so unsafely. For example, wearable technologies can give people the ability to leave the setting or can limit the unsafe exiting of residents whose person-centered plans document that they are at risk of doing so.
- Using tools and technology to monitor an individual's activities to promote optimal independence and personal autonomy, but assuring that such resources are not used in place of adequate supervision.
- Ensure that Medicaid beneficiaries who may wander or exit-seek unsafely carry identification with their name and the service provider's location and contact information.
- Create a back-up plan or lost-person plan that describes roles and responsibilities when an individual has exited in an unsafe manner.
- Evaluate each lost-person incident to make revisions to person-centered care plans or to environmental design as necessary.

Q4: How can residential and adult day settings promote community integration for people who are at risk of unsafe wandering or exit-seeking? What are some examples of promising practices for implementing the community integration requirements of the regulations defining home and community-based settings and simultaneously assuring the safety of individuals who exhibit these behaviors?

A4: All settings must facilitate and optimize Medicaid beneficiaries to live according to their daily routines and rituals, pursue their interests, and maximize opportunities for their engagement with the broader community in a self-determined manner, as outlined in the individual's person-centered service plan. The plan must reflect clinical and support needs as identified through an assessment of functional need, and document the individual's preferences for community integration and how these preferences will be addressed in the setting they have chosen.

Settings can support community integration, in accordance with each individual's person-centered plan by strategies and practices such as:

- Finding out during initial assessments what individuals desire in terms of community engagement and educate them about how the setting's capabilities will meet the individual's needs and preferences. This should be done before the individual makes a decision about services and settings to allow the best fit between the person and place.
- Documenting the factors the person identifies as important in a community such as proximity to and involvement of family, connections to communities of faith, specific cultural resources and activities, and others.
- Recording individual preferences for community integration in the person-centered plan and how the setting will support those preferences (e.g., participating in their faith community, attending a favorite club, Sunday breakfast at the local diner, interests in volunteering or in working, etc.) as well as the transportation needed to achieve desired outcomes, recognizing that many of these activities are leveraged through natural supports and thus would not require Medicaid-funded resources.
- Providing individuals with opportunities to engage others in their settings through activities, outings, and socialization opportunities.

- Providing sufficient staff and transportation to enable individuals' participation in their activities of choice in the broader community. These could include opportunities for work, cultural enjoyment, worship, or volunteering. The person-centered service plan may also include provider-facilitated opportunities to engage in desired activities in the broader community.
- Ensuring that visitors are not restricted, and individuals can connect to their virtual communities of choice through social media noting that this alone does not substitute for community activities and integration.
- Ensuring that individuals have opportunities to visit with and go out with family members and friends, when they want this. Providing an inviting environment and flexible schedules and service times (e.g., meals, medication administration) can encourage family and friends' participation in the life of the residential setting and support their efforts to maintain individuals' connections to the external community.
- Reviewing at least annually whether any parts of the person-centered plan need change. It is important to note that the modifications requirement within the regulations defining home and community-based settings also applies to anyone in a residential or non-residential setting, and thus the person-centered plan needs to document what services and supports should be made available to allow people to live where they want and do what they want during the day to assure maximum integration with the broader community. For more information on the HCBS rule requirements on person-centered planning, please refer to CMS' previous FAQs on this topic.

All settings, including those in rural communities and those in low density suburban areas, are encouraged to provide adequate transportation opportunities to meet beneficiaries' desires for meaningful community engagement and participation in typical community activities.

Note that visits by community members have value but do not substitute for community access for Medicaid beneficiaries receiving services in residential and adult day settings.