Addressing Wandering Behaviors in HCBS Settings

Eric Carlson

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Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources.

Since 1972 we’ve focused our efforts primarily on populations that have traditionally lacked legal protection such as women, people of color, LGBT individuals, and people with limited English proficiency.
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• Problems with getting on to the webinar? Send an e-mail to trainings@justiceinaging.org.

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When Practice and Policy Meet: Overview of the Federal Home & Community Based Services Rule

January 11, 2017
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Intent of the HCBS Settings Final Rule¹:  
**CMS 2249-F and CMS 2296-F**

- To ensure that individuals receiving long-term services and supports through home and community based service (HCBS) programs under the 1915(c), 1915(i) and 1915(k) Medicaid authorities have full access to benefits of community living and the opportunity to receive services in the most integrated setting appropriate.
- To enhance the quality of HCBS and provide protections to participants.

¹Published in the Federal Register on January 16, 2014, under the title, “Medicaid Program; State Plan Home and Community-Based Services, 5-year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice (Section 1915(k) of the Act) and Home and Community Based Services (HCBS Waivers (Section 1915(c) of the Act)).”
HCBS Setting Requirements

- Is integrated in and supports access to the greater community
- Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources
- Ensures the individual receives services in the community to the same degree of access as individuals not receiving Medicaid HCBS
- Is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting
- Ensures an individual’s rights of privacy, respect, and freedom from coercion and restraint
- Optimizes individual initiative, autonomy, and independence in making life choices
- Facilitates individual choice regarding services and supports and who provides them

**Additional Requirements for Provider-Controlled or Controlled Residential Settings**
Home and Community-Based Setting Requirements: 
*Provider-Owned or Controlled*

- Specific unit/dwelling is owned, rented, or occupied under legally enforceable agreement
- Same responsibilities/protections from eviction as all tenants under landlord tenant law of state, county, city or other designated entity
- If tenant laws do not apply, state ensures lease, residency agreement or other written agreement is in place providing protections to address eviction processes and appeals comparable to those provided under the jurisdiction’s landlord tenant law
Home and Community-Based Setting Requirements: *Provider-Owned or Controlled* (2)

- Each individual has privacy in their sleeping or living unit
- Units have lockable entrance doors, with appropriate staff having keys to doors as needed
- Individuals sharing units have a choice of roommates
- Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement
- Individuals have freedom and support to control their schedules and activities and have access to food any time
- Individuals may have visitors at any time
- Setting is physically accessible to the individual
Home and Community-Based Setting Requirements: Modifications of Provider-Owned or Controlled

• Modifications of the additional requirements must be:
  – Supported by specific assessed need
  – Justified in the person-centered service plan
  – Documented in the person-centered service plan
Home and Community-Based Setting Requirements: *Modifications of Provider-Owned or Controlled (2)*

- Documentation in the person-centered service plan of modifications of the additional requirements includes:
  - Specific individualized assessed need
  - Prior interventions and supports including less intrusive methods
  - Description of condition proportionate to assessed need
  - Ongoing data measuring effectiveness of modification
  - Established time limits for periodic review of modifications
  - Individual’s informed consent
  - Assurance that interventions and supports will not cause harm
Person-Centered Planning

• A key requirement for Medicaid HCBS providers
• Required effective 3-17-2014
• Providers who have focused on implementing strong person-centered planning practices can be valuable in demonstrating how it can be done.
Person Centered Planning in the Context of HCBS

- Individual Preferences
- Innovation in Supports & Use of Technology
- Person-Centered Plan
- Flexibility in Scheduling
- Leveraging of Natural & Paid Supports
Distinguishing between Settings under the HCBS Rule

Settings that are not HCB
- Nursing Facilities
- Institution for Mental Diseases (IMD)
- Intermediate care facility for individuals with I/DD (ICF/IID)
- Hospitals

Settings presumed not to be HCB
- Settings in a publicly or privately-owned facility providing inpatient treatment
- Settings on grounds of, or adjacent to, a public institution
- Settings with the effect of isolating individuals receiving Medicaid HCBS.

Settings that could meet the HCB rule with modifications
- Settings that are HCB but do not comport with one or more of the specific requirements outlined in the final rule.
- May require modifications at an organizational level, and/or modifications to the PCP of specific individuals receiving services within the setting.
- Must engage in remediation plan with the state, and complete all necessary actions no later than March 2019.

Settings presumed to be HCB and meet the rule without any changes required
- Individually-owned private homes
- Individualized supported employment
- Individualized community day activities
Settings PRESUMED NOT to Be Home and Community-Based: *Heightened Scrutiny*

These settings may NOT be included in states’ 1915(c), 1915(i) or 1915(k) HCBS programs unless:

• A state submits evidence (including public input) demonstrating that the setting does have the qualities of a home and community-based setting and NOT the qualities of an institution; AND

• The Secretary finds, based on a heightened scrutiny review of the evidence, that the setting meets the requirements for home and community-based settings and does NOT have the qualities of an institution
HCBS Statewide Transition Plans (STPs)

- Transition Plans
  - For 1915(c), 1915(i) and 1915(k) programs/services in effect prior to March 17, 2014
  - Includes 1115 Demonstrations and 1915(b)(3) services
  - Applies to settings

Note: New 1915(c), 1915(i) and 1915(k) programs and settings on or after March 17, 2014 must be in full compliance with HCB settings regulations at the time of approval.
Statewide Transition Plan Elements

• Evidence of the public notice process and results
• Systemic regulation and policy assessment
• HCB Settings assessment including settings presumed institutional in nature
• Remediation (systemic and settings specific)
• Proposed remedial strategies and timelines
• Monitoring to assure ongoing compliance
• Plan to assist individuals who may need to transition to another provider
HCBS Statewide Transition Plans: Status of STP Reviews

• One state (Tennessee) has received final approval from CMS.
• 19 additional states have Initial Approval
  – AK, AR, CT, DE, IA, ID, IN, KY, MT, ND, OK, OR, OH, PA, RI, SC, VA, WA, WV
• Rolling out of additional technical assistance to support states
  – Individual calls
  – Small Group State TA
  – SOTA Calls
  – Effective Models of Key STP Components
Looking Forward: HCBS Transition Plan
Implementation Timeline

- Final Rule
- Jan 2014
- Jan 2014 – March 2015

- Statewide Transition Development Period
- March 2015
- Mar- Sept 2015

- Statewide Transition Plans Due
- March 17, 2015
- 2016-mid 2017

- CMS Initial feedback to State on the STPs
- Fall/Winter 2015
- CMS review of Systemic Reviews
- 2017

- CMS review of Site Specific Assessments
- Ongoing 2017-2019
- CMS initial and ongoing review & feedback
- March 2019

- HCBS Compliance
- Ongoing

- Monitoring of Milestones
- 2018

- Today!
Review of HCBS Settings under Final Rule: 
*Key Components*

- Assessment
- Validation
- Remediation
Settings Assessment for HCBS Compliance: Threshold

- States are responsible for assuring that 100% of all HCBS settings comply with 100% of the final HCBS rule *in its entirety*.

- Quality thresholds should not be used to reduce the state’s requirement to assure 100% compliance across all settings.
HCBS Compliance in both Residential & Non-Residential Settings

• Individuals receiving HCB services must reside in settings that comply fully with the rule (regardless of whether those settings are being paid for using HCBS funds or not).

• Living in HCB settings that do not comply with the rule could jeopardize an individual’s ability to receive non-residential HCBS.
HCBS in Non-Residential Settings: 
*Promoting Community Integration*

**Access**
- Availability of supports to allow a person to engage in the broader community for the maximum number of hours desired daily.
- Activities designed to maximize independence, autonomy and self-direction.

**Variety**
- Broad range of activities/offerings that are comparable to those in which individuals not receiving HCBS routinely engage.
- Access to both individualized and small-group activities, on and off site.

**Quality**
- Cultural competency
- Measurement focused on Increasing Community Access, Decreasing Social Isolation
HCBS Implementation with Integrity: *Emerging Issues*

- Large congregate, facility-based settings should be carefully reviewed to determine whether they are presumptively institutional and/or identify remediation required to comply with the rule.
- Availability of single-units and roommate choices
- Unrestricted access to visitors, food and individual schedules
- Locked Units/Delayed Egress
- Control over personal resources
Where you live AND where you spend your day MATTERS under the HCBS rule.

How much Integration is Enough?

— *Reverse Integration* does not equal community integration, and this strategy by itself will not result in an appropriate level of compliance with the rule.

Implications of waiver/state plan service definitions and reimbursement structures
HCBS Implementation with Integrity: *Emerging Issues (3)*

- Person-Centered Planning with Fidelity
- Conflict of Interest in Case Management/Service Coordination and Service Delivery Process
- Strategies for Community Integration in both Residential & Non Residential
- Capacity Building/Training & TA
- Heightened Scrutiny – Settings that Isolate
- Planned Construction
- Wandering & Exit Seeking Behaviors/Memory Care
CMS HCBS Resources

• Main CMS HCBS Website:  [http://www.medicaid.gov/HCBS](http://www.medicaid.gov/HCBS)
  – A mailbox to ask additional questions ([hcbs@cms.hhs.gov](mailto:hcbs@cms.hhs.gov))

• Exploratory Questions
  • Residential Settings
  • Non-Residential Settings

• FAQs
  – HCBS FAQs on Heightened Scrutiny dated 6/26/2015
  – FAQs on Settings that Isolate
  – Incorporation of HS in the Standard Waiver Process
Strategies & Promising Practices for Addressing Dementia Care and Wandering Behaviors in HCBS Settings

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Justice in Aging Webinar
January, 2017
Wandering

• Wandering can be helpful or dangerous, depending on the situation.

• People may wander in response to:
  – An unmet basic need like human contact, hunger, or thirst
  – Boredom or a noisy, confusing environment
  – Some type of distress, like pain or the need to use the toilet.

• People who wander may gain social contact, exercise, and stimulation OR, they can become lost or exhausted.
Person-centered Services & Wandering/Exit-seeking in Community Settings (1)

• Key response is person-centered services.

• Person-centered service planning involves knowing people, their needs, preferences, and history, which helps service providers anticipate ways to meet needs and prevent injury for those who wander.

• Literature review concluded that, “Person-centered interventions are associated with positive influences on staff outcomes & improvement in the psychological status of residents and reduced agitation.”
Person-centered Services & Wandering/Exit-seeking in Community Settings (2)

• Service providers are likely to provide better services and supports when they:
  – Know the personal history of the individual with wandering/exit-seeking behavior
  – Know the person’s current health condition and remaining abilities
  – Know the situations or unmet needs that historically have triggered wandering/exit-seeking, their history and background
  – Try approaches to addressing wandering/exit-seeking that respond to the person’s unique circumstances and needs.
Person-centered Service Plan Goals when Wandering/Exit-seeking Occurs

- Service plan goals are to:
  - Encourage, support, and maintain a person’s mobility and choice, enabling him or her to move about safely and independently
  - Ensure that causes of wandering/exit-seeking are assessed and managed, with particular attention to unmet needs
  - Prevent unsafe wandering/exit-seeking.
Practice Recommendations (1)

The research and practice literature recommends specific approaches to responding to wandering/exit-seeking. They generally involve the following:

• Assessing the patterns, frequency, and triggers for wandering/exit-seeking through observation and talking with people who have these behaviors and their families or friends

• Using this baseline information to develop a person-centered service plan to address these triggers, implement the plan, and measure its impact

• Using periodic assessments to update information about a person’s wandering/exit-seeking and adjust the person-centered service plan as necessary.
Practice Recommendations (2)

• Using “environmental design” and other strategies to address unsafe wandering/exit-seeking, for example:
  – Eliminating overstimulation, such as visible doors that people use frequently; noise; and clutter
  – Preventing under-stimulation by offering activities that engage interest. Activities could include music, art, physical exercise, mental stimulation, therapeutic touch, pets, or gardening
  – Providing a safe, uncluttered path for people to wander that has points of interest and places to rest
  – Using signage to orient the individual to the environment, such as indicating location of toilets and bedrooms
  – Disguising exit doors using murals, if safety codes permit.
Practice Recommendations (3)

• Using technological solutions as part of a person-centered service plan to alert others so that they can reduce the risks of wandering/exit-seeking.

• Recommending that people who may wander/exit-seek unsafely carry identification with their name and the service provider’s location and contact information.

• Using “Silver Alert” systems in those states that have them.
Practice Recommendations (4)

• Police departments may have registries where, with permission, people can fill out a short form, so if a person wanders, officers can find out how best to communicate with him or her, and get other important information.

• Creating a lost-person plan that describes staff and safety personnel’s roles and responsibilities when an individual has exited unsafely.

• Evaluating each lost-person incident to make revisions to person-centered service plans or to environmental design as necessary.
Practice Examples from the Field (1)

• Help the person feel comfortable in new settings and monitor them closely for a few weeks, if they are at risk of wandering/exit-seeking.

• Distract the individual at risk of unsafe wandering/exit-seeking with something he or she enjoys (e.g., rocking in a rocking chair, reading, eating ice cream) rather than saying no.

• Support opportunities for safe wandering. Circular paths with benches and railings for rest and balance can help. They can:
  – Be indoors and outdoors
  – Be free of trip hazards
  – Have discreet visual shields/distractions/barriers/silent alarms.
Practice Examples from the Field (2)

• Be aware of cues for exiting and use strategies to address them:
  – Engage the person in meaningful activities after meals
  – Distract the person at times of shift change.

• Post signs at doors asking visitors not to leave with anyone other than the person they came with or asking them to alert staff when they leave so the exit can be monitored.

• Use of webcams or closed-circuit TVs at exits, especially those exits that staff cannot easily observe. Note that providers generally need to get permission from staff and a sign must be posted about the presence of the webcam or TV.
Practice Examples from the Field (3)

• Adequate supervision may vary from resident to resident and from time to time for the same resident. The following tools can help to monitor a resident’s activities, but do not eliminate the need for adequate supervision:
  – Use silent alarms to alert staff if a person who tends to wander/exit-seek enters a risky area
  – Use medical ID bracelets, when they are part of a person-centered service plan, so emergency personnel know whom to call if they find a person who has exited unsafely.
Practice Examples from the Field (4)

• Clearly label important doors:
  – Shadowboxes or collages with personal items on the door to people’s rooms
  – Photos of a toilet could be a reminder of the bathroom

• Frosting of glass doors or windows can reduce a person’s ability to look out. Make sure this complies with fire/safety codes.

• Many states will permit window locks so the window cannot be opened more than 6 inches.
Person-centered Services & Wandering Resources (1)


- ACL has resources available about person-centered dementia services at: http://www.nadrc.acl.gov/

- VA has resources:
  - Staff Educational Toolkit on Wandering for Community Living Centers: http://www.audio.va.gov/visn8/MP4/Managing_HD_YouTube_HD_1080p.mp4

- Alzheimer’s Association has practice recommendations at: http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp.
Person-centered Services & Wandering Resources (2)


- The Down Syndrome Society has information at: [http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease](http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease)

- Practice recommendations for people with Down syndrome from the National Task Group on Intellectual Disabilities and Dementia Practices: [http://aadmd.org/ntg](http://aadmd.org/ntg)

Person-centered Services & Wandering Resources (3)

- ACL webinar for District of Columbia on Person Centered Thinking: [https://www.youtube.com/user/AoA25](https://www.youtube.com/user/AoA25)
- ACL No Wrong Door Training Link: [http://directcourseonline.com/pcc/](http://directcourseonline.com/pcc/)
Thank you!

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CMS FAQs on Wandering Behavior


• Reliance on
  • Person-centered planning.
  • Staff training.
  • Care delivery.
• “... while responding to unsafe wandering and exit-seeking behavior in an individualized manner.”
  • FAQs, p. 1.
High Expectations for Person-Centered Planning

- Process driven by the beneficiary.
- Assistance from a trained assessor, care manager, or similar facilitator.
- Input from people important to the beneficiary, while still reflecting the beneficiary’s input as much as possible.
  - FAQs, p. 2.
More Details on Planning Process

• Informed by discussions with family members or other important persons.
• Focuses on beneficiary’s strengths and interests.
• Outlines the beneficiary’s reaction to various communication styles.
• Identifies the beneficiary’s favorite things, and disfavored things.
  • FAQs, p. 2.
Recommendations in Planning Process

• Proposing experiences that the beneficiary may enjoy as community engagement.

• Describing factors or characteristics that beneficiary would find isolating or stigmatizing.
  • FAQs, p. 2.
Training Topics for Service Providers re: Wandering Behavior

• Conditions that lead to wandering behavior.
• Differentiating between conditions and, on the other hand, other factors such as mental illness or overmedication.
• Assessing beneficiaries for co-occurring conditions.
• Understanding past instances of unsafe wandering.
Training Topics (cont.)

- Principles of
  - Person-centered planning and
  - Person-centered care.
- Strategies for identifying and handling behavioral expressions of need or distress.
- FAQs, p. 2.
Planning Practices Specific to Persons with Wandering Behavior

• Assessing wandering behavior through direct observation and talking with beneficiary and (as appropriate) family.

• Using this baseline information to develop, implement, and evaluating a plan.

• Conducting follow-up assessments and adjust plan accordingly.
  • FAQs, p. 3.
Can “Controlled-Egress” Settings Qualify for HCBS?

- Yes, if the provider complies with the requirements for modifying the standards based on a person-centered plan.
- Setting must show individual determinations of risk, and individual accommodations for those who are not at risk.

- FAQs, p. 3.
Contents of Plan If Controlled Egress Is Used

• Beneficiary must understand safety features, including controlled egress.

• List of choices for preventing unsafe wandering.

• Consent from beneficiary and representatives to controlled egress.

• Services and supports that enable beneficiary to participate in desired activities.

• Listing of options that were explored before decision to use controlled egress.

  • FAQs, p. 3.
Can Beneficiary Be Limited Within Setting?

• “... 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.”

• FAQs, p. 4.
Comments and Editorializing: Authority for Modifications

• Note that the modification procedures by their terms apply only to certain requirements for provider-owned or –controlled settings, and not to the general requirements applicable to all HCBS settings.

• See 42 C.F.R. § 441.301(c)(4)(vi)(F).

• But possibly the details of community integration may vary in the case of wandering behavior.
The Right Result

- From a public policy perspective, wandering behavior should not be a disqualifier for HCBS.

- Important to emphasize that locked settings, controlled egress, etc., should not be seen as the first and only option for persons with wandering behaviors.
Real-Life Person-Centered Planning

• Beneficiary’s HCBS provider may not develop the person-centered service plan (except if no other entity is available.)
  • 42 C.F.R. § 441.301(c)(1)(vi).
• In provider-owned or –controlled settings, the Medicaid service plan generally authorizes the services, and the facility service plan has details about the beneficiary’s day-to-day activities.
Example (1 of 3)

- Anxiety: “Support client by assisting with activities/medications designed to prevent further complications. Prevent behavior that could contribute to mental health exacerbation. Compliance with medications, emotional stability, and engaged in supportive behavior.”
Example (2 of 3)

- Risk of Falls: “Supervision of medications, safety of environment, and use of appropriate personal devices. Identify issues that could impair ability to avoid falls. No falls reported.”
Example (3 of 3)

• Impaired Skin Integrity: “Implement turning, repositioning schedule. Utilize pressure relieving devices. Apply dressings as ordered. Resolution of compromised areas, no further damage acquired. Skin will be intact, no erythema noted on assessment.”
Please Send Examples
Questions?

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