HCBS SOTA Call Series

HCBS Rule & Wandering/Exit-seeking

July 27, 2016

Part One of a 2-part Series

Intent of the HCBS Settings Final Rule[1]: CMS 2249-F and CMS 2296-F

- To ensure that individuals, who are 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.

[1]Published 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

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES
CENTER FOR MEDICAID & CHIP SERVICES

HCBS Rule Highlights Related to Community Access

- The home and community-based setting requirements establish an outcome-oriented definition that focuses on the nature and quality of individuals' experiences.

- The requirements maximize opportunities for individuals to have access to the benefits of community living and to receive services in the most integrated setting.

- The person-centered service plan must be developed through an individualized planning process.

- The person-centered planning process is driven by the individual.

- Includes people chosen by the beneficiary and/or the beneficiary's representative, which may include a variety of individuals that play a specific role in the beneficiary's life (ie. members of the beneficiary's interdisciplinary team, family members, friends, individuals providing natural supports).

- Provides necessary information and support to the individual to ensure that he or she directs the process to the maximum extent possible.

- Is timely and occurs at times/locations of convenience to the individual, his or her representative and others engaged in the beneficiary's person-centered service planning process.

- Reflects cultural considerations/uses plain language.

- Includes strategies for solving disagreement.

- Offers choices to the individual regarding services and supports the individual receives and from whom.

- Provides method to request updates.

- Reflects what is important to the individual to ensure delivery of services in a manner reflecting personal preferences and ensuring health and welfare.

- Identifies the individual's strengths, preferences, needs (clinical and support), and desired outcomes.

- May include whether and what services are self-directed, and includes risks and plans to minimize them.

- Includes individually identified goals and preferences related to relationships, community participation, employment, income and savings, healthcare and wellness, education and others.

- Signed by all individuals and providers responsible for its implementation and a copy of the person-centered service plan must be provided to the individual, his or her representative, and others chosen by the beneficiary.

Strategies & Promising Practices for Supporting Individuals who Wander/Exit-seek Unsafely in HCBS Settings

CMS SOTA Call: Part 1 in a 2-part Series

July 27, 2016

Today's Featured Subject Matter Expert Presenters

- **Jane Tilly, DrPH**
  - Senior Policy Advisor, Center for Policy Evaluation Administration on Community Living, USHHS

- **Doug Pace**
  - Director, Alzheimer's & Dementia Care
    Alzheimer's Association

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 (PCS) & Wandering/Exit-seeking in Community Settings (1)

- Key response is person-centered services (PCS).

- PCS 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."

PCS & 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

PCS 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 with 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 or covering door handles 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.

- Creating a lost-person plan that describes 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 closed-circuit TVs at exits, especially those that staff cannot easily observe

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.

PCS & 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
  - Satellite broadcast on Dementia: Getting Lost in the Community: http://www.audio.va.gov/visn8/MP4/Dementia_LOST_SD_YouTube-Vimeo_SD_480p.mp4 .

- Alzheimer's Association has practice recommendations at: http://www.alz.org/professionals_and_researchers_dementia_care_practice_recommendations.asp.

PCS & Wandering Resources (2)

- UNC and CEAL's *Toolkit for Person-Centeredness in Assisted Living – An Informational Guide and Questionnaires of Person-centered Practices in Assisted Living (PC-PAL)* available at http://www.shepscenter.unc.edu/news_release/new-free-questionnaires-can-improve-care-quality-life-older-adults-assisted-living-person-centered-practices/.

- The Down Syndrome Society has information at: 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.

- The National Autism Association has a safety-related site at: http://nationalautismassociation.org/resources/naas-autism-safety-site/

THANK YOU!

Jane Tilly, DrPH

Senior Policy Advisor

Administration for Community Living

jane.tilly@acl.hhs.gov

202-795-7454

Implementing the HCBS Rules in Settings Serving Individuals with Dementia and Other Cognitive Disabilities

July 27, 2016

Doug Pace

Director – Alzheimer's & Dementia Care, Alzheimer's Association

Vice Chair – Center for Excellence in Assisted Living

Alzheimer's Association: Vision and Mission

OUR VISION:
A world without Alzheimer's disease®.

OUR MISSION: To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

alzheimer's association®

THE BRAINS BEHIND SAVING YOURS:

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research.

We enhance care and support

- The Association works on a global, national and local level to enhance care and support for all those affected by Alzheimer's and other dementias. We are here to help.

We advance research

- As the largest nonprofit funder of Alzheimer's research, the Association is committed to accelerating the global progress of new treatments, preventions and ultimately, a cure.

www.theceal.org

Board Member Organizations

Assisted Living

- 713,00 residents nationwide
- 22,200 communities/ 408,000 employees
- State regulated – state regulations vary
- 70% women/30% men
- 53% 85+ 83% 75+
- **40% have Alzheimer's or related dementias**
- 81% private pay (personal finances/LTC insurance) 19% Medicaid
- Memory Care Units fasting growing segment

• Medicaid Program; HCBS Final Rule

- – "In this final rule, CMS is moving away from defining home and community-based settings by 'what they are not,' and toward defining them by the nature and quality of individuals' experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics."

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule

CEAL Comments to CMS 2-26-16

CEAL's History with HCBS Attributes & Person-Centered Care

- **Person-Centered Care in Assisted Living: An Informational Guide**

- **Person-Centered Care Domains of Practice: General Home and Community-Based Services Attributes and Assisted Living Indicators**

- **Toolkit for Person-Centeredness in Assisted Living – An Informational Guide and Questionnaires of Person-Centered Practices in Assisted Living (PC-PAL)**

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (2)

- Community Engagement/Avoiding Isolation
  - As noted by Norris-Baker and Scheidt, "… *it is important to recognize that strong emotional attachment to community may take different forms, depending on individual variations in sense of place, and that although shared bonds to neighborhood, community, region, type of environment [urban, rural], or even nation are important for many people, it is not a universal phenomenon. Emotional attachments and meanings attributed to communities may vary greatly and change over time."* Carolyn Norris-Baker and Rick J. Scheidt, "On Community as Home: Places that Endure in Rural Kansas," (*Home and Identity in Late Life: International Perspectives,* Graham D. Rowles and Habib Chaudhury (editors), Springer Publishing Company: New York, 2005, p. 281).

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (3)

- Secured Assisted Living Communities Designed to Serve People with Dementia
  - Many times, a move to dementia-specific assisted living occurs when the family cannot meet the needs of the person affected by the disease and when they are no longer safe in their own homes because they are at heightened risk of unsafe exit seeking.
  - 40% of residents in residential care communities have a diagnosis of Alzheimer's disease of other dementias
  - 6 in 10 people with Alzheimer's disease will engage in "wandering" behavior at some point over the course of the disease.
  - Balancing safety and autonomy

alzheimer's association®

THE BRAINS BEHIND SAVING YOURS:

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (4)

CEAL comments to CMS 6-29-16

- <u>Theme #1:</u> If individual person-centered service planning is important to every person, it is doubly important for those people living with dementia.
  - "No one size fits all" approach will never be successful
  - "The nature and quality of individuals and experiences" is critical when it comes to PCS planning and delivery.
    - They change over time as people -
      - Age
      - Lose a spouse
      - Distance of children
      - Changes in their community surroundings
      - Changes in their underlying health conditions and disability status

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (5)

- *Practices that providers should adopt to demonstrate acceptable person-centered dementia services planning include:*
  - *Service plans that are uniquely tailored to the needs and preferences of each individual resident;*
  - *Service plans that show evidence of meaningful involvement of the resident in the discussions or decisions related to the services he or she receives;*
  - *Service plans that show evidence that residents were offered alternative service approaches designed to meet their individual needs and preferences;*
  - *Service plans that defer to decisions made by the resident or their designated representative.*
  - *Service plans that discuss individual preference for community integration within and outside the residential setting and how the provider will assist in that integration through provider assistance, flexibility in scheduling meals/medication administration/personal care services, and provider coordination of 3rd party and volunteer services.*

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (6)

- <u>Theme #2:</u> A corollary to the first theme is that effective PCC delivery must rest on effective communications with residents living with dementia that is grounded in building relationships, not just providing needed services.
  - Listening
  - Observing
  - Learning about each individual's life story
  - Interpreting what is seen and heard
  - Relating to each person as an individual

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (7)

- In order to promote effective communication that is the core of PCC planning and service delivery, management should provide education and training materials regarding ways to communicate with residents living with dementia. Training programs should include important information on issues such as:

➢ Types of dementia, their causes and how they affect the individual's ability to function;

➢ Stages of dementia and what to expect over time;

➢ Principles of person-centered service planning and delivery;

➢ Strategies for handling behavioral expressions of need or distress.

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (8)

- Theme #3: Good communications and PCC planning and service delivery can mitigate behavioral expressions of need or distress that are often misunderstood and labeled as abnormal or anti-social, including unsafe exit seeking, but safety concerns may require some form of secured egress from buildings.
  - Even very effective and dedicated programs for providing PCC for people living with dementia noted that they employ ways to secure egress from the building to address safety concerns, but they stressed that secured egress alone is not an adequate response to exit seeking behaviors.

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (9)

- As the [Dementia Practice Guidelines](#) from the Alzheimer's Association note, "The behavior and emotional state of people with dementia often are forms of communication because residents may lack the ability to communicate in other ways."

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (10)

- For some, exit seeking may simply be an attempt to have a pleasant walk, to get outside and get a bit of exercise.
- Exit seeking may also be motivated by human needs that the person may have difficulty communicating, such as the need for human interaction or hunger or thirst.
- Some exit seeking may be related to patterns of daily routines and types of community engagement that may have been disrupted by the move to assisted living.
- Some exit seeking may be an attempt to express distress regarding aspects of the residential environment, such as noise, other residents, and restrictions on access to exterior spaces or unpleasant interactions with staff members.

CEAL's Recommended Strategies & Promising Practices for Implementing Person-Centered Dementia Care in Assisted Living under the HCBS Rule (11)

- Conclusion
  - Providing person-centered services to people living with dementia presents some of the most challenging issues in promoting the objectives of honoring individual preferences and enabling community engagement as required by the final HCBS rule.
  - Some features of residential life, such as controlled egress, may place some limitations on personal freedom.
  - However, denying Medicaid HCBS funding on this basis would only mean that residents are forced into more restrictive institutional settings that generally do not have the same PCC requirements or orientation.
  - CMS must make some balanced judgments in this area regarding the trade-offs between personal choice and safety.

Thank You

Doug Pace

Director, Alzheimer's & Dementia Care

Alzheimer's Association

1212 New York Ave NW

   Suite 800

Washington, DC 20008

202-638-8661

dpace@alz.org

Questions?

- CMS HCBS rule: ralph.lollar@cms.hhs.gov

- Wandering/Exit-seeking Practice: jane.tilly@acl.hhs.gov

- Assisted living settings: dpace@alz.org