



Realizing the Vision of Optimal Community Inclusion:

Additional Strategies for States & Providers in
Implementing the HCBS Settings Rule with Fidelity





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RULE & WANDERING EXIT-SEEKING BEHAVIOR



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
 - 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.

Person-Centered Services & 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!

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***Strategies for Promoting Optimal Engagement in the Broader Community
via Integrated Day and Employment Supports Under HCBS***

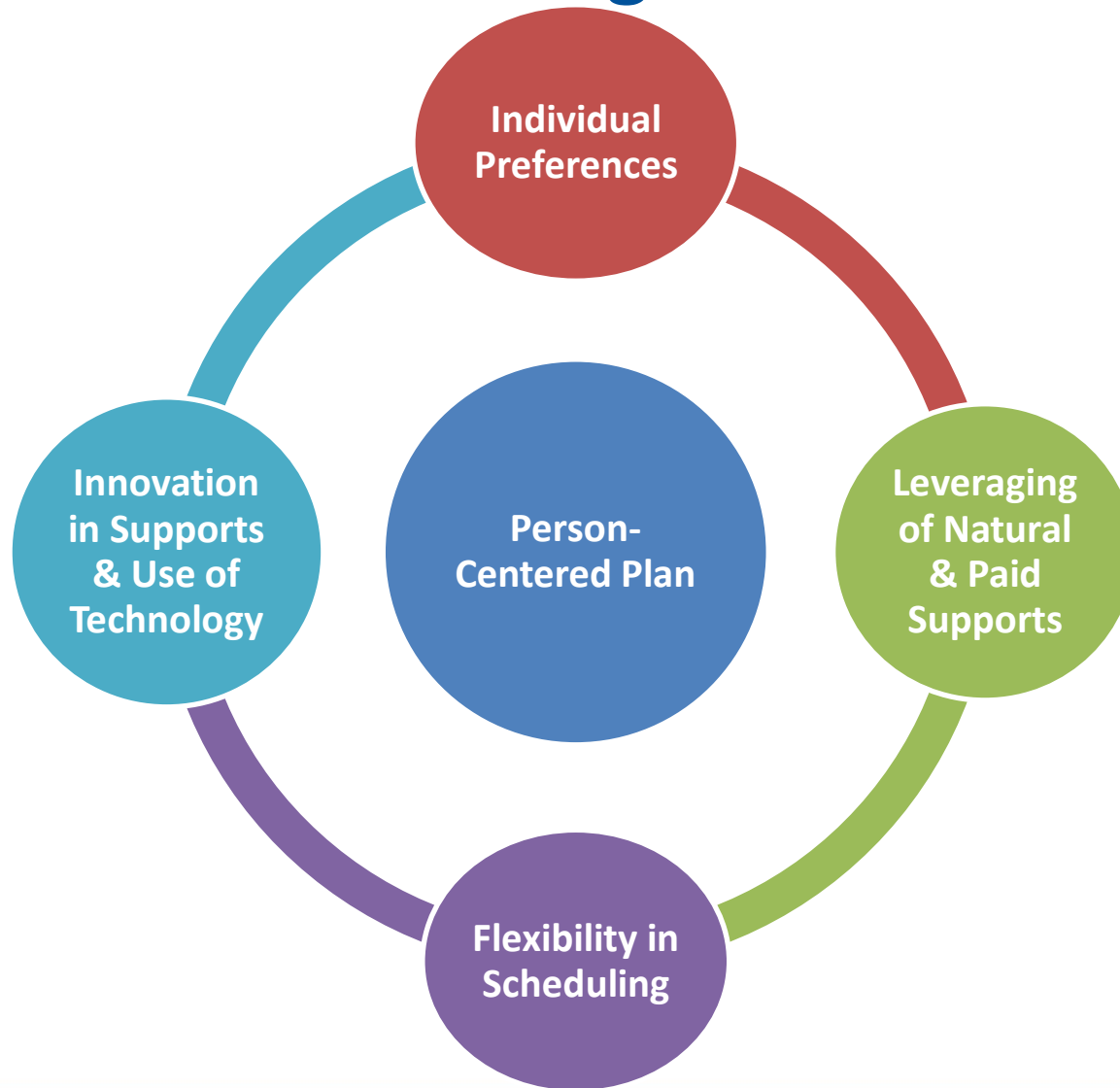
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IMPLEMENTING HCBS IN NON- RESIDENTIAL SETTINGS



Person Centered Planning in the Context of 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 in Non-Residential Settings: *Promising Practices (1)*

- *Spending time with HCBS beneficiaries in natural environments and exposing beneficiaries to a number of community-based experiences as a way to better inform the person-centered planning and follow-along assessment processes.*
- *Developing partnerships and alliances with generic, community-based entities that result in mainstream inclusion of HCBS beneficiaries in activities available within the broader community.*
- *Establishing public relations programs that highlight and incentivize stronger engagement of community-based partners directly with HCBS beneficiaries.*
- *Establishing a community-based advisory group to help identify and design new models and strategies for the setting to expand its individualized service offerings and increase greater access to activities in the broader community.*

HCBS in Non-Residential Settings: *Promising Practices (2)*

- *Reaching out to local businesses and community partners to request program/activity/event discounts and free memberships for individuals receiving HCBS similar to offerings provided to aging Americans, military service personnel/veterans, and other special populations.*
- *Exhausting public transportation options (including ride shares, taxi services, public metro or bus systems, trains, virtual transportation services, etc) to promote optimal individualization of scheduling and activities.*
- *Fostering access to technology, virtual applications, and other innovations as a way to stimulate natural supports and provide solutions-oriented strategies to facilitate greater participation in activities by HCBS beneficiaries in the broader community.*
- *Offering activities and programs that encourage families and friends to participate regularly and that promote greater independence and autonomy on the part of HCBS beneficiaries.*

HCBS in Non-Residential Settings: *Promising Practices (3)*

- *Assuring the level of support required, appropriate staffing levels , and adequate transportation options needed to offer both group and individualized options that facilitate optimal community engagement.*
- *Decentralizing staff structures so as to promote greater flexibility and encouragement of community-based staffing over facility-based staff structures.*
- *Hiring of logistics coordinator or purchasing of logistics software to help facilitate and promote increased individualization and small group activity scheduling.*

HCBS in Non-Residential Settings: *Promising Practices (4)*

- *Collaborating with providers of similar settings to share administrative functions and leverage resources focused on training and ongoing capacity building of managers and front-line staff in the implementation of effective practices that result optimal community integration of HCBS beneficiaries.*
- *Designing activities that may begin as a small group endeavor but allow for some individualization and individual personal growth and development as part of the activity.*
- *Emphasizing community-based activities that promote the development of skills and facilitate training and educational opportunities among HCBS beneficiaries that could lead to attaining and expanding competitive, integrated employment opportunities.*
- *Facilitating skills-building workshops and activities that encourage greater control over personal resources and promote increased independence and personal autonomy of HCBS beneficiaries.*

HCBS in Non-Residential Settings Focused on Aging Beneficiaries: *Strategies*

- *Promising practices for non-residential HCBS settings focused on aging beneficiaries to consider incorporating in an effort to promote greater access to the broader community and increased personal autonomy include but are not limited to:*
- *Design of multiple daily activities and access to the broader community through a combination of natural supports, formal community partnerships, and formal programming that allows for each individual to be able to select from an array of individual and/or group options and control his or her own schedule.*
- *Provision of services in a culturally competent way, with options that meet the needs of diverse populations such as limited-English proficient older adults.*

HCBS in Non-Residential Settings Focused on Aging Beneficiaries: *Strategies*

- *Opportunities designed to enable individual HCBS beneficiaries to attain or maintain as much independence as possible and to decrease social isolation.*
- *Availability of sufficient levels of well-trained staff, including staff that is knowledgeable about each person, in order to allow the person to engage in a meaningful day with positive experiences.*
- *Readily available transportation provided in a way that promotes ease of access for older adults and optimizes individuals' ability to select their own options and make decisions about their services and supports. Transportation should include individually planned and delivered options to allow maximal participation in community life. Availability of public transportation may not be a sufficient strategy to foster access to the broader community.*

HCBS & Non-Residential Settings:

Employment

- **Facility-Based Employment:** Access to employees without disabilities? Same exposure to typical community settings and the public to the same degree as their non-disabled coworkers? Ability to leave the facility during the day and engage with typical community settings for lunch, breaks, etc.?
- **Supported Employment:** In the case of group supported employment, what steps are the states taking to assess these settings and make any needed modifications?
- **Aging & Employment:** Beneficiaries who wish to be supported in pursuing employment must have access to such supports via HCBS setting offerings, though it is recognized that many aging beneficiaries do not wish to seek employment.

HCBS & Non-Residential Settings: *Employment Resources (1)*

Administration for Community Living Resources

- ***ACL's Partnerships in Employment Systems Change Grants:***
<http://www.acl.gov/Programs/AIDD/Programs/PNS/Resources/PartnershipsInEmplSystemsChangeGrants.aspx>
- ***ACL's Community of Practices:***
<http://www.acl.gov/Programs/AIDD/Programs/PNS/Resources/CommunityOfPracticeProjects.aspx>
- ***ACL's No Wrong Door Program:***
<https://www.adrc-tae.acl.gov/tiki-index.php?page=PersonCentered>

HCBS & Non-Residential Settings: *Employment Resources (2)*

Office of Disability Employment Policy Resources

- **ODEP National Employment First Online Policy & Data Platform:**
www.employmentfirst.leadcenter.org
- **Criteria for Performance Excellence in Employment First State Systems Change and Provider Transformation:** <http://employmentfirst.leadcenter.org/employment-first-resources/criteria-for-performance-excellence-in-employment-first-state-systems-change-provider-transformation>
- **Federal Funding & TA Opportunities that Support State Employment First Efforts**
<http://employmentfirst.leadcenter.org/employment-first-resources/federal-resources-available-to-support-state-employment-first-efforts>
- **ODEP 50-State Analysis of HCBS Waiver Non-Residential Rates:**
<http://employmentfirst.leadcenter.org/employment-first-resources/review-of-hcbs-data-for-day-employment-services-for-all-50-states-and-dc>.
- **National Employment First State Leadership Mentoring Program's Community of Practice:** <http://econsys.us6.list-manage.com/subscribe?u=29aa515bd6e4d1a3e196930b4&id=63a8e8be13&subscribe>

HCBS & Non-Disability Specific Settings: *Strategies*

- *Invest in capacity building activities of existing and new providers to assure the development of multiple non-disability specific setting options across all categories of home and community-based services offered by the state.*
- *Provide ongoing training and technical assistance needed to help address systems-wide remediations of specific settings.*
- *Disseminate information to existing and potential provider entities about any local or state tax or other financial incentives available for establishing non-disability specific HCBS setting options in the state.*
- *Review existing HCBS service definitions, policies, and rate structures to assure outcome-oriented, incentives-based approach to HCBS, including but not limited to promoting innovative transportation and natural support strategies that facilitate individual community integration.*

HCBS & Non-Residential Settings: *Emerging Issues*

- Large congregate, facility-based settings should be carefully reviewed to identify **if remediations** are needed to comply with the rule.
- *Reverse Integration* does not equal community integration, and this strategy by itself will not result in an appropriate level of compliance with the rule.
- Group v. Individualized
- Implications of waiver/state plan service definitions and reimbursement structures

Modernizing HCBS: *Tips from Innovative Providers*

- Invest time and resources into effective practices.
- Build your social capital at all levels.
- Explore traditional and non-traditional revenue sources.
- Do it one person at a time, and do it a lot of times until you're done. You'll get better at what you do.
- Start small – clear the path. Don't get stuck in planning, processing and waiting for the right “time” for change.
- Hire for who you want to become, not for who you are.

Modernizing HCBS Non-Residential Settings: *Innovative Provider Service Principles*

- The best places to learn how to live and work in the community are in the community.
- Our buildings should be places for people to come and go – not to stay.
- We shouldn't provide things here that exist naturally in the community.
- We should never make the people we support look incompetent in the community



Thank you!

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