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Michael Nardone  
Director  
Disabled and Elderly Health Programs Group  
Centers for Medicare & Medicaid Services  
7500 Security Boulevard  
Baltimore, Maryland 21244

May 20, 2016

Dear Mr. Nardone,

The Alzheimer's Association appreciates the opportunity to continue our discussion around home- and community-based services (HCBS) for persons with dementia. We applaud CMS's recognition of the special needs of this population and the agency's willingness to clarify how HCBS can help to meet those needs.

Although CMS intends to define settings by the "nature and quality of individuals' experiences...rather than one based solely on a setting's location, geography, or physical characteristics,"<sup>1</sup> it has also stated that certain settings--as determined by their locations (adjacency to a hospital), geography (farmsteads), and physical characteristics (controlled egress)--are presumed ineligible to serve HCBS recipients until a heightened standard of proof is met. For this reason, states and settings serving persons with dementia require further guidance, which we understand CMS is currently developing. The Alzheimer's Association hopes that the following discussion of this population's special needs and innovative settings and practices will assist CMS its guidance development. Below we address three areas of the rule and existing guidance that affect persons with dementia, and we respectfully suggest language that we believe will help CMS realize the goal of HCBS: to ensure individuals' independence, health, and quality of life through choice, control, and access to a full array of quality services.

### **Integration and "Isolating" Settings**

The final HCBS rule and subsequent guidance around settings focuses almost exclusively on *physical* integration with a community. The Alzheimer's Association fully supports all individuals' right to access and interact with the community around them to the extent they are able and so wish. But for reasons discussed below, unfettered access to larger communities can be dangerous for some individuals with dementia. Thus, in addition to ensuring the broadest possible access to one's physical surroundings, we encourage CMS to consider and add emphasis to other ways individuals are integrated into their immediate communities. Regardless of location and physical features, settings and staff can bring people into equal, meaningful participation with their chosen surroundings. Some best practices are discussed below. This approach is consistent with CMS's focus on the nature and quality of individuals' experiences.

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<sup>1</sup> Centers for Medicare & Medicaid Services. (2014). *Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule (CMS 2249-F/2296-F)*, <https://www.medicare.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/hcbs-setting-fact-sheet.pdf>.

*Suggested Language:*

States must continue to promote individual preference and need with regard to a person's chosen setting. In addition to exploring opportunities for individuals to access their broader physical communities, states should give weight to other means by which individuals are meaningfully integrated into their immediate settings, such as how a setting fosters relationships and community internally and externally.

**Controlled Egress**

As we have noted in past comments, wandering is a prominent safety concern for many individuals with Alzheimer's disease or other dementias. Six in ten people with Alzheimer's disease will wander. As affected persons' memories fade, they are unable discern where they are or where they are supposed to be. For example, they may try to fulfill former obligations, such as going to work. But the decline in their other cognitive skills, like judgment and problem solving, creates safety risks. They may wander to an unfamiliar place or may not be able to recognize dangerous situations. Families frequently try to address these behaviors in the home for as long as possible: they provide their loved ones with structured routines and activities to distract them from wandering or they lock doors and windows. Often, however, these measures are not enough for families who cannot provide constant supervision. For these families, residential and day memory care programs with means of controlled egress can provide safe, specialized environments designed to meet the needs of persons with cognitive impairment.

"Controlled egress" is the regulation of how an individual leaves a place, not confinement. These are systems which prevent doors from opening immediately in non-emergency situations. Means of controlled egress designed to prevent wandering come in many forms. These can range from signals to staff when a door is opened to doors that open after a 15-second delay to a keypad with a coded release. All systems are designed to open in life-threatening emergencies. But just as importantly, facilities providing high-quality care employ other effective strategies to deter wandering: continuous walkways, access to safe outdoor spaces, calming surroundings, and stimulating, personalized activities designed to foster community and a sense of independence.

Beyond controlled egress, settings that successfully balance personal safety with autonomy and engagement offer comprehensive approaches to keeping residents/attendees safe, healthy, and active. Physical layouts include indoor and outdoor spaces that allow residents to move freely between community areas and private rooms. They provide extensive person-centered activities designed to engage residents in ways that cater to their capabilities and routines.

We also note for CMS's consideration that many adult day care programs for persons with dementia offer much more integration with their external communities than if those people were to remain at home all the time. For attendees with Alzheimer's and other forms of dementia, adult day centers provide a chance to be social and to participate in activities like music, exercise, and supportive counseling or therapy.

*Suggested Language:*

Any setting employing means of controlled egress must assess an individual with cognitive impairment and document the individual's need for safety measures in his or her person-centered care plan. The plan should document: 1) discussion of the setting's safety features, including any means of controlled egress,

with individuals and their caregivers and/or representatives and 2) consent from the individual and caregivers/representatives. The plan should also document the individual's preferences and opportunities for engagement within the setting's community and with the broader community.

### **Heightened Scrutiny**

The Alzheimer's Association understands CMS's concerns regarding "settings that isolate" and that the agency, through its "heightened scrutiny" standard, seeks to ensure that individuals explore all options to be as integrated as possible into their broader communities. However, states require clarification of the standards that settings must not "have the qualities of an institution," and should "have the qualities of home and community-based settings." CMS should consider all the ways a person can be integrated into his or her immediate and broader surroundings and give appropriate weight to personal preference and needs.

#### *Suggested Language:*

States may submit information for any setting serving persons with dementia that may have institutional qualities. Evidence should address the extent to which any setting using controlled egress measures offers opportunities to interact with the broader community and efforts made to integrate persons into the immediate community. With regard to his or her integration, evidence should address the incorporation of an individual's preferences, choices, and experiences. States should refer to the following list of examples of evidence they may submit to satisfy the heightened scrutiny standard for these settings.

1. Examples of person-centered service plans that document cognitive and physical assessments, risk assessments, and justifications for restrictions
2. Documentation that persons with dementia and their caregivers/representatives have selected and consented to the setting of choice and have been informed of all safety measures, including controlled egress measures
3. Documentation that an individual who has been assessed as cognitively and physically able to safely leave the setting is able to do so independently without restriction
4. Documentation that an individual who has been assessed as unable to safely leave the setting independently is able to leave escorted in accordance with his or her person-centered service plan
5. Documentation of an individual's preferences and opportunities to engage within the setting and with the broader community
6. Evidence of personalized/individualized service and care and "homelike" settings, such as unique room decor, flexible meal times/food options, options for varied activities, and how individual privacy is protected and respected
7. Written assurances that interventions and supports, including any form of controlled egress, will cause no harm to the individual

8. Evidence of individual assessments for opportunities for meaningful engagement in both organized and spontaneous activities (e.g., an evaluation of a person's history, preferences, strengths, and abilities), engagement with members of the community, and "social roles" for individuals
9. Evidence of staff training in person-centered care and efforts to know individuals, including their preferences, goals, history, strengths, and capabilities
10. Evidence of strategies to enhance relationships among residents/attendees and between residents/attendees and staff
11. Evidence of ongoing efforts to foster relationships within the setting and between the setting and the broader community, such as open houses and outreach groups (e.g., gardening clubs) hosted by the setting
12. Evidence of being able to receive visitors at any time
13. Evidence of quality improvement processes that rely on feedback of residents/attendees, caregivers/representatives, family members, and staff
14. Evidence of common areas that encourage interaction and stimulation and safe outdoor space readily accessible to individuals
15. Evidence of a setting's physical design promoting community engagement and features that foster a sense of independence and movement without barriers
16. Evidence of programming that promotes individual dignity, socialization, and expression

Application of the above examples of evidence to a hypothetical setting using means of controlled egress and other measures to protect residents who are at risk for wandering can satisfy the standard and honor individuals' dignity and independence.

- The complete needs and preferences of residents/attendees are evaluated and documented. For example, in addition to assessing a person's physical health, he or she completes a "lifestyle biography" that captures favorite pastimes, traditions, communication style, preferences, history, accomplishments, memories, and family and friends.
- The setting works with residents/attendees and families to identify opportunities to leave the grounds--for appointments, for entertainment, for travel.
- If a residential setting, residents furnish and decorate their private units.
- Staff receive ongoing dementia-specific training.
- The setting employs a wide range of programming: small-group activities that help residents socialize around common interests, therapy for persons in the advanced stages

of the disease, and readily accessible individual activities based on interests, hobbies, and lifelong habits.

- The setting serves as a resource to its surrounding community, offering family and caregiver support groups, education, and training.
- The physical layout of the setting offers private bedrooms (if residential), multiple common areas, visual cues to orient residents/attendees, and continuous walking paths both indoors and outdoors.

The Alzheimer's Association also notes for CMS's consideration Oregon's rules on memory care communities (OAR chapter 411, division 57).<sup>2</sup> The rules establish the required endorsement of facilities that serve persons with dementia in secured environments. The rules are written to promote a "...positive quality of life...person directed care...dignity, choice, comfort, and independence." The rigorous endorsement process includes protections for individual dignity at every step. For example, the initial application for endorsement must include a copy of the care planning tool and employee training curricula. Facilities are required to develop and implement life enrichment and family support programs. Staff must be trained in person-directed care and services must be delivered in "a manner that promotes autonomy and dignity...and maintain[s] or enhance[s] the resident's remaining abilities for self-care." Structured and unstructured activities based on resident assessment and preference are required. Any controlled egress measures must allow for visitor entry. CMS and states serving persons with dementia should look to Oregon's framework.

The Alzheimer's Association is grateful for the opportunity to help CMS strengthen HCBS for persons with cognitive impairment and their families and welcomes future discussions. Please contact Laura Thornhill, Manager of Regulatory Affairs, at 202/638-7042 or [lthornhill@alz.org](mailto:lthornhill@alz.org) if we can be of further assistance.

Sincerely,



Robert Egge  
Executive Vice President, Government Affairs

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<sup>2</sup> OAR ch 411, division 57, [https://www.dhs.state.or.us/policy/spd/rules/411\\_057.pdf](https://www.dhs.state.or.us/policy/spd/rules/411_057.pdf).