Center for Excellence in Assisted Living (CEAL) comments submitted to the Centers for Medicare and Medicaid Services (CMS) on guidance for implementing the HCBS Final Rule

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I. Introduction

The Center for Excellence in Assisted Living (CEAL) applauds the efforts of the Centers for Medicare and Medicaid Services (CMS) to define what “home” and “community” mean in order to promote person-centered care (PCC) for those receiving Medicaid services. Beyond simply complying with civil rights laws such as the Americans with Disabilities Act, CMS is laying the foundation to support providing services to people with disabilities of all ages grounded in and directed by the experiences of each individual in meeting his or her own needs and preferences.

Having made similar efforts, the members of CEAL appreciate the opportunity to suggest guidance on community integration as it relates to assisted living (AL) and some commonly found models (see Section III) as well as the specific circumstances in secured dementia assisted living communities (see Section IV). CEAL can appreciate the difficulty of defining and operationalizing the terms “home” and “community,” when they are experienced in such different ways by each individual. After several attempts at different approaches, CMS noted the evolution of its approach in its online Fact Sheet entitled “Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings 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 supports this focus on the “nature and quality of individuals’ experiences,” fully realizing that goal will require clear and appropriate guidance from CMS and the states on critical issues that have arisen. Specifically, our memo discusses two major issues that could undermine the goal of focusing on individuals’ experiences: 1) defining “qualities of an institution,” either by virtue of being “isolating” or because of location near to institutional settings; and 2) addressing specific issues raised by AL communities serving people with dementia that have secured egress. Each section includes a background discussion of the issues with some embedded hyperlinks to further information followed by suggested guidance language that CMS might use in italics.

II. CEAL’s History with Home and Community-Based Services Attributes and Person-Centered Care

The Center for Excellence in Assisted Living (CEAL) was founded in 2004 by eleven stakeholder organizations dedicated to the vision of “a society that supports quality of life for all individuals and their right to age with respect and dignity.” Among CEAL’s “guiding principles,” is that the organization supports assisted living communities that “[a]re person-centered, consumer driven and actively engaged with the community at large.”

In collaboration with researchers from the University of North Carolina (UNC), Chapel Hill, CEAL has focused attention in recent years on how to conceptualize and operationalize that vision and guiding principle, resulting in a number of publications that we recommend to CMS and to the states as they develop guidance for implementing the CMS rule for HCBS.

A. Person-Centered Care in Assisted Living: An Informational Guide

This first publication developed the conceptual framework for identifying HCBS attributes and person-centered care in assisted living, and stipulated that:

> "[t]he core principles of PCC include the assurance of individuality, choice, privacy, dignity, respect, independence, a sense of being part of a community and connected to the larger community, and a home environment in which to reside. Interestingly, although not often explicitly recognized, the pioneers of assisted living also embraced similar principles in its foundational culture."

Fundamental to this effort was recognizing that achieving person-centered care must involve all aspects of the operation of an AL community. Specifically, the report identified the following nine domains of an operational framework for person-centered assisted living:

- Person-centered core values of personhood, respect & dignity, autonomy, choice & independence, and privacy
- Relationships and a sense of belonging (community)
- Governance (ownership, board of directors)
- Leadership
- Workforce practices
- Meaningful life and engagement
- Services
- Environment
- Accountability

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

Recognizing that different communities will have different ways to achieve desired outcomes, this second document translates the nine domains above into observable indicators such as: "Organization can demonstrate how it supports and facilitates individual access to the greater community in other locations beyond the setting and through electronic means other communities of interest."

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

This third document provides specific and practical guidance to providers about how to translate the HCBS indicators into their daily operations. Together, these three documents demonstrate CEAL's commitment to achieving the HCBS attributes essential to person-centered care and may serve CMS and states well as they develop specific guidance on implementing the HCBS rule.

III. Community Engagement/Avoiding Isolation

Several points follow from the CMS focus on "the nature and quality of individuals' experiences" that are critical to providing clear and appropriate guidance to states and providers as they implement the HCBS rule. The first point is the diversity of individual experiences of home and community. 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).

As this insightful summary of the research indicates, the nature of community engagement differs not only among different types of people, but also over time for individuals as they experience life-changing events such as widowhood, loss of friends, disability, or neighborhood changes. Homes and communities that once were anchors for personal identity and community engagement can become isolating as the person's abilities change and the surrounding environment changes. Assisted living (AL) arose as a housing-based, consumer-driven alternative to institutional services for older people whose disabilities have made it difficult to remain in their homes. For those who have become isolated in their own homes, moving to an AL community may increase "community engagement" by providing greater opportunities to engage others living in the building.

Activities coordinated by the AL setting can also bring the larger community into the AL community, and staff support, volunteer coordination, and transportation services provided or arranged by the AL community can enhance the ability of residents to engage in the communities of their choice. For some residents, connecting the person to the virtual communities available through social media may be an important avenue to community engagement. Guidance should encourage all of these approaches as part of assisted living communities' efforts to achieve "community engagement" for their residents.

To make this feasible, many older individuals choose locations with or near family members who often have become central parts of their "community." Such individuals may be indifferent to the fact that a nursing home or hospital is next door – indeed, they may find such proximity to be a convenience rather than isolating. In their experiences, it may be much more important to their community engagement that they are near family members who provide support and enable the person to engage in activities outside of the AL community. Guidance should include providing an inviting environment and flexible schedules and service times (e.g., meals, medication administration) to encourage family participation in the life of the AL community and to support family members' efforts to maintain residents' connections to the external community.

A second important point is that the diversity of individual experiences and preferences must be matched by a diversity of AL communities. No one AL community can meet the preferences of all potential residents when it comes to community engagement. An essential element of ensuring community engagement is assessing individual needs and preferences before making a decision about services and settings to allow the best fit between the person and place.

CEAL is concerned about the potential consequences of CMS guidance related to the new HCBS rule regarding setting characteristics considered to be institutional in nature. This guidance could especially affect:

- Secured dementia units/neighborhoods within a larger AL community or as a free standing community;
- Continuing Care Retirement Community (CCRC) type arrangements where AL is located on the same campus as independent living and a nursing home (NH);
- AL that was built as a separate section of a NH or is a converted section of a NH;
- AL that is on the campus of or adjacent to a hospital or other healthcare provider;
- AL communities located at the edge of town or in a rural area that could be considered isolated.

While not prohibited by the HCBS rule, such settings could be presumed to have the qualities of an institution unless the state and CMS determines that they are home and community based through a process of "heightened scrutiny." It is CEAL's understanding that heightened scrutiny does not mean additional standards for complying with the HCBS rule. Rather, AL communities that require heightened scrutiny would have a greater responsibility to demonstrate to the state and CMS that they are meeting the same HCBS requirements for person-centered care and community engagement as other similar providers.

CEAL appreciates the clarity provided by CMS in its guidance regarding CCRCs: "In CMS' experience, most Continuing Care Retirement Communities (CCRCs), which are designed to allow aging couples with different levels of need to remain together or close by, do not raise the same concerns around isolation as the examples above, particularly since CCRCs typically include residents who live independently in addition to those who receive HCBS." Such guidance might also be extended to other settings where assisted living communities are located adjacent to a nursing home, but also have easy proximity to residential and commercial areas that enhance community engagement.

It is critical to honoring consumer preferences and opening opportunities for Medicaid beneficiaries that CMS also provide greater clarity regarding the heightened scrutiny process. In the absence of such clarity, states may simply issue blanket prohibitions of these types of AL communities. For example, CEAL has learned that recently the Virginia Medicaid agency was informed by CMS that the Alzheimer's Assisted Living Waiver could not meet the requirements of the new CMS HCBS Final Rule. It is our understanding that CMS stated even under heightened scrutiny secured/locked communities are not acceptable. The risks associated with a lack of clarity and the fear of increased compliance burdens may also discourage providers from accepting Medicaid beneficiaries or developing new affordable AL communities, decreasing access to this important HCBS option for consumers and increasing the likelihood that they will be forced into nursing homes.

As CEAL understands the process, in cases where AL communities are suspected of having the qualities of an institutional setting, states will make a determination of whether they qualify as HCBS providers based on information gathered from such providers as well as information from public comments, state inspections, and other sources. From these determinations, the state Medicaid agencies will develop transition plans and waiver applications that are subject to public comment. After making revisions based on public comments, the state will submit its application to CMS. CMS will review each state's application and may accept or reject the application or its determinations of the HCBS eligibility of specific communities. Providers should have the right to appeal any negative determinations by state agencies or by CMS.

CEAL recognizes that some types of AL raise specific issues regarding opportunities for community engagement by virtue of their location. CEAL also recognizes that state policies have sometimes used Medicaid funded services to segregate and isolate people with disabilities. But, in correcting this historical problem and truly honoring consumer preferences, it is important to remember that assisted living arose as a consumer driven alternative to institutional settings, not as the result of state Medicaid policies. Moreover, a person-centered approach requires the recognition that the location issues most likely to be priorities for older consumers are such factors as proximity to family, whether the community meets their preference for a rural, suburban, or urban setting, or whether the AL community is located in their current neighborhoods where they can continue to be involved in faith-based, social, and other community activities. People should be able to select the type of AL community that makes them feel most at home and best promotes the types of engagement important to them.

To the extent that a preferred AL community may exhibit some "qualities of an institutional setting" as enumerated in CMS guidance, states should clarify alternative means of demonstrating their home and community-based qualities (e.g., individualized transportation, recruiting and organizing volunteer companions to get residents to desired community functions or gathering places, etc.). Regardless of the setting's location or potential for isolation, person-centered plans should record individual preferences for community integration and how the assisted living community will support those preferences (e.g., participating in their long-time faith community, attending a favorite bridge club, Sunday breakfast at the local diner, etc.).

CMS guidance to states should address the right of residents to best match their needs and preferences to the available options. Once individuals have selected their service and setting options, Medicaid HCBS providers have a responsibility to address community engagement preferences documented in the individualized care plan through a combination of staff, family, and volunteer efforts as needed to achieve desired outcomes. Some aspects of individual priorities for community engagement can only be addressed and trade-offs made at the time a person makes the decision about where to live and receive services. CMS recognized this in its approach to private rooms. As the final rule states: “The setting 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. The setting options are identified and documented in the person-centered service plan and are based on the individual’s needs, preferences, and, for residential settings, resources available for room and board.”

CMS guidance should clarify the equal importance of assessing individual preferences when it comes to the choice of types of community engagement. Care/case managers – whether they are employed by state Medicaid agencies, Area Agencies on Aging, Aging and Disability Resource Centers, or Managed Care Organizations – should include assessments of each individual’s preferences regarding community engagement when they do initial assessments of functional needs. CMS could further support individuals in avoiding isolation from their communities of choice by providing additional guidance to states on how to counsel beneficiaries in making decisions about which communities best address their needs and preferences for engagement and the need to honor those individual choices.

Guidance focused on the individual’s preferences will be important to honoring those preferences and priorities that may not align with the positions of some advocates or clinicians. For example, current CMS guidance describes settings that isolate: “The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities.” This guidance could discourage many models that are currently hailed as best practices in assisted living and supportive housing in terms of bringing health-related services and social activities to people where they live. Moreover, it could deny Medicaid eligible individuals the very preferences that have been expressed by the market behavior of many older private pay consumers.

Bringing the external community on site through faith-based, social, entertainment and recreational activities can be a way of promoting community engagement. Providing opportunities to engage in the broader community is necessary, but forcing frail elders to leave the AL setting for community engagement in some cases can be a real hardship and even unsafe. Discouraging such services and activities because they are defined as isolating would only deprive people of their benefits – in many cases, without increasing their contacts with the broader community. Offering services and activities on site does not eliminate the need to provide transportation and other access to services and activities that are in the broader community, but such practices should be encouraged as a form of community engagement, not discouraged by guidance that suggests they are indicators of disqualifying isolation.

Suggested CMS guidance language regarding the Heightened Scrutiny Process:

The final rule regarding home and community based settings describes conditions under which residential settings are presumed to have "qualities of an institutional setting" by virtue of their location, which include "Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS…" States should not interpret these conditions as blanket prohibitions regarding the HCBS benefits. Rather, these conditions should trigger a process of "heightened scrutiny," under which providers have the opportunity to demonstrate that they meet the goals of person-centered services planning and delivery and the community engagement of beneficiaries.

Heightened scrutiny does not require additional regulatory HCBS standards. Rather, CMS intends to "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." States must establish heightened scrutiny processes that require residential settings presumed to have the qualities of an institutional setting to demonstrate that they can achieve acceptable outcomes for beneficiaries regarding person-centered services planning and delivery and community engagement as required by the HCBS rule. Settings where most or all residents are receiving Medicaid assistance must demonstrate that they are providing comparable levels of community engagement as similar settings where most residents are not receiving such assistance.

During the heightened scrutiny process, states can rely on the following types of evidence demonstrating that a setting is meeting the requirements of HCBS providers:

- *Person-centered services plans document each resident's preferences for community engagement and records ways those preferences have been addressed;*
- *Settings provide or arrange for transportation to opportunities for community engagement in the broader community;*
- *Settings document evidence of working with family, friends, and volunteers to enable community engagement opportunities in the broader community;*
- *Settings bring opportunities for community engagement identified in the person-centered service plans on site to the assisted living community; and*
- *Settings coordinate on site activities based on information from person-centered services plans that reflect individual interests.*

After gathering evidence regarding compliance with HCBS requirements, states must make a determination regarding each setting's status as an eligible HCBS provider. Those providers determined to be in noncompliance must be given a limited time to come into compliance and a right to appeal those decisions. States will compile their HCBS determinations into a report to be submitted as part of transition plans and waiver applications to CMS. Prior to submission, this report must be subject to public comment and the state's report to CMS must include any actions taken as a result of the public comments received.

Suggested Guidance Language regarding Setting Location and Community Engagement

Opportunities for community engagement are often best achieved at the time when beneficiaries are making decisions about the services and settings they need and prefer. In order to achieve the goal that "[t]he setting is selected by the individual from among setting options…," states should require that assessment instruments used to develop initial person-centered services plans that guide decisions about Medicaid services and settings include not just functional needs but also an assessment of the individual's preferences regarding community engagement. Whether they are employed by state Medicaid agencies, Area Agencies on Aging (AAAs), Aging and Disability Resource Centers, Managed Care Organizations or other entities, care/case managers should be trained to identify those factors that individual beneficiaries experience as most important in "community engagement" and those factors or characteristics that they find most isolating or stigmatizing.

Potential beneficiaries should be informed about all options that may be available, "including non-disability specific settings and an option for a private unit in a residential setting." Such a process should also include the range of other factors the individual identifies as important in a community such as proximity to family, family inclusive policies and practices, connections to communities of faith, specific cultural resources and activities, and others. The process should also identify individual preferences regarding community services that are in proximity as well as any features such as location on the campus with health-related providers. The goal is to identify the best match between the individual's needs and preferences regarding community engagement and the options available. The match between the individual beneficiary's preferences and the assisted living community's services should be reviewed at least annually to determine continued compatibility.

No matter what setting is selected, all HCBS providers have an obligation to enable people to maximize their engagement with the broader community. All providers, including those in rural communities and those in low density suburban areas, must demonstrate adequate transportation opportunities beyond providing the means to doctor appointments that allow people to engage in community activities they choose. Providers should demonstrate how they involve family members in the life of the assisted living community and enable residents to participate in family activities. Providers that share a building with a nursing home or are adjacent to a healthcare provider must especially demonstrate how their operations are driven by person-centered services planning and how they actively promote the engagement of residents with the broader community.

IV. Secured Assisted Living Communities Designed to Serve People with Dementia

Settings specifically designed to serve people with dementia, especially those with secured egress, raise special problems with respect to compliance with the HCBS rule. According to 2014 data collected by the National Center for Health Statistics, 40 percent of residents in residential care communities have a diagnosis of Alzheimer's disease or other dementia. As would be determined in the individualized person-centered care plan, people in the early and middle stages of Alzheimer's disease and other dementias frequently do not need extensive nursing services but do need the kind of personal care assistance available in AL to meet daily needs. Many consumers and their families seek out specialized assisted living because of the special activities and programming tailored to the needs of those living with dementia as well as the resources such communities can provide to ensure the safety of those living with dementia.

Assisted living designed for people living with dementia provides the same person-centered services and community life as non-specialized AL, but with some modifications that recognize the special needs of people living with dementia as the disease progresses. For example, the design of the building can aid way finding, modified lighting can help reduce sundowning symptoms, or food can be modified as finger food for those who can no longer use utensils. Even details, like eliminating potentially toxic items, require special awareness and staff training to assure the safety of those living with advancing dementia. Responding to the growing demand for such communities, industry data indicate that memory care communities are the most rapidly growing segment of the senior housing and services sector (compared to independent living, regular assisted living, and nursing homes). CEAL believes that the benefits of AL communities should be available as an option for those living with dementia who must rely on Medicaid HCBS.

A common manifestation of dementia is walking about, often referred to as "wandering" behavior – indeed, the Alzheimer's Association reports that six in ten people with Alzheimer's disease will engage in "wandering" behavior at some point in the course of the disease. People with dementia who are walking about may appear to be engaged in purposeless "wandering", but to the individual, such walking about is often linked to purposes that are clear to them. Best practices should be employed by providers to understand walking about behavior, minimize potentially dangerous exiting seeking (sometimes referred to as "elopement"), and allow for access to the outdoors and safe walking. The high risks and the unpredictable nature of exit seeking, however, does suggest the need for special measures to assure the safety of residents. Uncontrolled egress has resulted in unnecessary tragedy in some cases. 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.

Some provisions, such as lockable doors on individual rooms or apartments, are amenable to making individual determinations of need and inclusion in individualized person-centered service plans. Security provisions that are characteristics of the setting, such as controlled egress, present special issues when it comes to individualized planning. One time for a decision about whether such characteristics are warranted is at the point of selecting a setting to live in. Consumers and, when appropriate, their family or surrogate decision-makers should be informed of the options for dementia services in a variety of settings, including specialized AL communities with controlled egress. Eliminating this option as per se isolating would mean that many Medicaid beneficiaries living with dementia will not have access to AL services for which there is demonstrable demand in the private pay market, forcing many into nursing homes who would not otherwise have needed to move there.

Once a person makes a choice to move into an AL community with secured egress, the provider still has a responsibility to develop person centered service plans that balance decisions involving autonomy versus risk for each person while continuing to protect the safety of all residents. For example, spouses who are not living with dementia should have the ability to come and go by giving them the code to an electronically controlled exit. Technological solutions, such as electronic pendants that identify those who have been identified as at risk of exit seeking, may be used to allow freer egress for those residents who have not shown a risk of exit seeking. Family and friends should also have unrestricted access. AL communities with secured egress should be able to demonstrate how they can make individual determinations of exit seeking risk and make individual accommodations for those who are not at risk. For individuals at risk of exit seeking, providers have a responsibility to facilitate continued community engagement though the person-centered care planning process – meeting individual preferences through a combination of paid and volunteer resources. It is not acceptable for a provider to conclude that individuals at risk of exit seeking cannot continue to enjoy and benefit by community engagement outside of the secured community.

Suggested CMS guidance language regarding Secured Assisted Living Communities:

Prior to relocation, Medicaid beneficiaries living with dementia and, where appropriate, their families and surrogate decision-makers should be informed about the range of service options and settings for dealing with the debilitating aspects of the disease, including home services and the range of residential options. The person-centered plan developed by the care manager – in cooperation with the individual's representative where appropriate – must document the individual's preferences for community engagement and how those preferences could be addressed in the setting of their choice. Among the choices may be dementia-specific communities, including those with secured egress. Beneficiaries and their representatives should be informed of how the secured egress will limit the resident's ability to come and go as they please and what opportunities the residential setting offers or coordinates for engagement with the broader community.

Providers of dementia-specific residential communities must demonstrate that their operations and services are driven by person-centered planning for each individual. Providers should also assure that residents and their representatives, when appropriate, are involved in the person-centered planning process and decisions are made consistent with their needs and preferences. Individual living spaces should include lockable doors unless an individual determination is made that such an arrangement is unsafe. Such a determination must be documented in the person-centered services plan and periodically reviewed to make certain that such a restriction continues to be necessary.

Residential communities with secured egress must make individual determinations regarding residents for whom unrestricted egress would be unsafe. Such a determination must be documented in the person-centered services plan and reviewed periodically to make certain that such restrictions continue to be necessary. Providers can demonstrate in a variety of ways that they permit egress for residents who are not at risk of unsafe exit seeking. For example, wearable technologies may permit egress among those residents who have not shown a risk of exit seeking while restricting the unsafe exiting of those who have *shown such a risk. Family and frequent visitors must be given unrestricted access as with any other assisted living or independent living setting. Residents must have unrestricted access to secured outdoor spaces or regular escorted access to locations and activities outside of the setting as provided in the person-centered services plan. Providers with secured egress must have systems that automatically provide unrestricted egress in the event of a fire or other life safety event in accordance with local building codes. The person-centered service plan should also include provider-facilitated opportunities to engage in desired activities in the broader community.*

Conclusion

In promulgating this rule, CMS has taken a major step in charting the future of home and community-based services for people of all ages with disabilities. It has done so at a time of great change in the delivery of such services – as consumer preferences, professional practices, and technological change are driving more long-term service and support options in more locations than ever. In addition, healthcare reform and technological change are making more health-related services available in more settings. CEAL applauds the effort to place consumer needs and preferences in the center of the planning and delivery of such services. We believe that issuing this suggested guidance would enhance the implementation of this rule and the successful achievement of the goals of person-centered services and community engagement. We look forward to working closely with CMS to accomplish those goals.