HOME & COMMUNITY-BASED SETTINGS RULE

How Regulation Intended to Ensure Access to Medicaid Funded Services Falls Short, and Changes Needed to Fix It

July 2023

LeadingAge®

The Home and Community-Based Settings (HCBS) Rule, also called the "Olmstead Rule" (the Settings Rule), presents more barriers than solutions for older adults who use aging services. The Settings Rule aims to protect the civil rights of people who use home and community-based services funded by Medicaid by ensuring that the services provided are separate and distinct from institutions. The Rule's final effective date, March 17, 2023, increases the urgency of the need to recognize that many of its provisions do not apply to services for older adults, and, in reality, may preclude the ability of older adults to choose home and community-based services and force them, unnecessarily, into institutional placements for lack of alternatives.

HCBS services for older adults do not fit neatly into the two distinct categories contemplated by the Settings Rule—community or institutional. In the case of aging services—particularly adult day and assisted living—the Settings Rule is having the chilling effect of ***limiting access to HCBS*** for older Medicaid beneficiaries, leaving nursing homes as the only available option. This paper presents a case, with examples, demonstrating that the Settings Rule conflicts with the reality of the needs of older people who use aging services, and, in fact, poses threats to the Rule's own intent.

LeadingAge proposes that CMS treat services for older adults differently than services for working-aged individuals with disabilities, and immediately place a two-year moratorium on enforcement of the Settings Rule for adult day and assisted living providers serving primarily individuals with dementia or over age 55, and use the time to develop compliance guidance for these provider groups. If the current enforcement landscape continues, we anticipate many aging services providers, particularly assisted living and adult day, will cease to accept Medicaid payments and there will be a chilling effect on the expansion of these vital Medicaid services. This lack of access will have the opposite effect of the Rule's intent: Over time, more beneficiaries—who would have otherwise elected community-based care—will likely end up in nursing homes.

EXECUTIVE SUMMARY

Years in the making, the CMS Home and Community-Based Settings (HCBS) Final Rule[1], was published in 2014 but the effective date was delayed until March 17, 2023. The Settings Rule was a historic step forward in protecting the civil rights of people who use Medicaid home and community-based services. It came in direct response to a 1999 Supreme Court ruling (*Olmstead*) that found Medicaid programs were discriminating against long-term care users by not offering them the most integrated settings of care.

States and the federal government partner to administer Medicaid programs serving eligible individuals in nursing homes and community-based settings. Through the eligibility and administration of these programs, the *Olmstead* ruling outlined that some individuals were unnecessarily institutionalized on the basis of their disability status, functionally denying their right to not face discrimination in public services (i.e., preventing them from having access to services in the most integrated setting) as spelled out in the Americans with Disabilities Act. The Settings Rule

[1] Accessed 4/6/23: https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider

was highly controversial and required a lot of effort to implement, hence the long delay to the final effective date. From the beginning, it was never a good fit for aging services.

By attempting to label all providers as either institutional or community-based, pain points emerged for providers of services to older adults. These providers work to promote dignity in aging, while meeting the individual's long-term care needs. They help participants and residents retain existing skills, and assist with health, mental health, and functional support as the course of aging erodes long-held skills.

The Settings Rule further stands in contrast to the trend in aging services for provider organizations to offer an array of services and settings across the continuum of care. Older adults who need help with activities of daily living experience changes in functional status and need different levels of care during their final years. Offering multiple services on a single campus or through a single provider allows people to remain as independent as possible without having to move to a completely different community, or possibly not requiring an individual to transition from their familiar and long-attentive provider. In addition, it enables couples to remain in close proximity, even when one of the individuals needs a higher level of care.

States have made tremendous strides in expanding access to home and community-based services as federal incentives like the Balancing Incentive Program, or options like the 1915(k) program, offer enhanced federal financial participation. With this progress, we must not forget the landscape under which the Settings Rule was born. Providers are now operating in a completely different environment than when the Settings Rule was proposed and even from when it was finalized. For the most part, the changes are beneficial—there is a greater understanding and corresponding regulatory environment around what it means to be person-centered. This progress is to be applauded. We must not muddy this progress with regulation that will cause regression for older adults and the providers who serve them.

The paper looks at themes in the Settings Rule—community integration, physical environment, and separation from other settings—and corresponding requirements within each theme. We outline why these requirements do not fit with the needs of older adults. We also propose policy solutions—starting with halting Settings Rule enforcement for aging services until older adult-centered guidance can be developed.

INTRODUCTION

The Settings Rule requires HCBS services to be integrated into their communities and promote activities and interactions that people not living with disabilities would experience. The government determined those kinds of activities included, among other provisions, trips away from home, employment, decisions about when and what to eat, and decisions about when and what kinds of supports would facilitate the most independence. Just as each of us decide if and when we are going to the grocery store or movies, what training we might desire in order to secure employment to provide for our families and support the greater fabric of our functioning society, the Settings Rule was developed, proposed, and implemented to codify those rights among people needing and receiving supports through the Medicaid-funded long-term care system.

The Settings Rule was conceptualized in the mid-2000s when many states hadn't adequately tackled desegregation of people with disabilities following the 1999 Supreme Court decision[2] on Olmstead. First proposed in 2008, then revised, and later finalized in 2014, the landscape of providers and our understanding of community settings has drastically evolved. Many of the now-presumed institutional settings that must undergo heightened scrutiny would have transcended the expectation of community integration under the standards of operation with which policymakers were familiar in 2006 and 2007.

The overarching vision of the Settings Rule is important for individuals of all ages. Medicaid beneficiaries must be guaranteed access to person-centered services delivered in a way that ensures their dignity and freedom from coercion and restraint. The devil is in the details. Some of those details simply do not apply to services for older adults.

Members of LeadingAge who provide adult day or assisted living services report a wide range of state approaches to the enforcement of the Settings Rule for aging services providers. Some report that state officials know the Settings Rule doesn't apply well to their services and "look the other way." Others have told us that questions have been raised and they've undergone heightened scrutiny and been deemed compliant. Still, others are put through documenting compliance case by case, even though a requirement is inconsistent with the services provided. And some are found to be non-compliant.

This rule will chill access. It already is doing so: in April 2023 we learned of one state Medicaid agency that decided not to add assisted living to the state's offerings because of concerns about being able to demonstrate compliance with the Settings Rule. This rule does not fit older adults. Specific examples of components of the rule that do not fit with aging services make up the majority of the rest of this paper.

To highlight one example, in March 2023, CMS visited a memory care unit within an assisted living provider. From the onsite review, CMS penned a letter to the State of Kansas outlining a number of areas of non-compliance with the Rule. The memory care unit was urged to seek partnerships with public transportation, taxis, and ride shares to allow residents to better integrate into the community. To be clear, the individuals conducting heightened scrutiny on behalf of CMS in this community are urging the provider to encourage the use of public transportation for residents with dementia.

From an on-site review of another assisted living provider with a memory care unit in Wichita, Kan., surveyors outlined areas of rule noncompliance for failure to offer volunteer opportunities or employment counseling during the person-centered planning process. CMS said, "The setting should ensure that individuals are informed of their choices for competitive, integrated employment." More explicitly here, CMS is requiring that individuals with dementia be offered employment counseling and community volunteer opportunities.

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[2] Accessed on 4/13/23: https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html#:~:text=The%20U.S.%20Supreme%20Court's%201999,with%20Disabilities%20Act%20(ADA).

These three examples are illustrative of what LeadingAge and others have known about and noted throughout this long implementation process: that the Settings Rule is not fit for older adults. But the enforcement of the final compliance date is underscoring the devastating impact this policy is going to have on older adults and those who serve them. We can do better. We can be truly person-centered in our approach while also protecting the rights of and supporting the diverse needs of different populations. We must not lose the spirit of the Settings Rule's objectives: to provide the optimal services in the most appropriate setting in a manner that the participant decides as we view our current landscape and the implications for compliance.

THE CHARACTERISTICS OF OLDER ADULTS WHO USE HCBS AND THE SERVICES THEY USE

Two commonly used Medicaid community-based services for older adults are adult day/adult day health services and assisted living. The Settings Rule does not make sense for these two services and the people who use them.

Older adults use adult day services because they have physical or cognitive disabilities and need support, services, and/or supervision. Most adult day participants live with family caregivers in the community. Adult day services provide health-related, social, psychological, and behavioral benefits, especially for those with dementia and other cognitive impairments, while at the same time enabling caregivers to work, care for their families, and attend to their own health and well-being. Adult day services promote and support caregivers so they can help their loved ones remain in the community.

Most adult day services participants are over age 65, with 19% over age 85. Almost all need help with activities of daily living (ADLs); two-thirds of them need assistance with three to six activities such as bathing, toileting, dressing, and walking. More than half cannot get out of a chair without help[3].

In 2018, the most recent year for which data are available, there were about 4,200 adult day service providers (though many were closed during the pandemic and did not reopen), serving more than 250,000 participants. More than two-thirds of adult day participants are Medicaid beneficiaries; most would be eligible for a nursing home placement in their state.

Assisted living is not a federally regulated setting and varies among states. Assisted living services can be delivered in communities of affordable housing, or within a set of apartment-style units within an assisted living provider. Typically, services include but are not limited to meals, medication monitoring, assistance with ADLs, and round-the-clock emergency response. Unlike adult day services, only 16% of assisted living residents are Medicaid beneficiaries. Because assisted living is considered a home and community-based service under Medicaid, reimbursement rates do not cover room and board. Nevertheless, nearly 150,000 Medicaid HCBS users live in an assisted living setting in one of the 47 states that include assisted living as a Medicaid-covered service.

[3] Accessed 5/13/2023: https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf

More than half of assisted living residents are older than 85, with another 30% between age 75 and 85. Over 40% have dementia; the most common supports used by assisted living residents are bathing, locomotion, and dressing.

ILLUSTRATING THE CHALLENGE: EXAMPLES OF THE INAPPLICABILITY OF THE SETTINGS RULE TO OLDER ADULTS

In this section, we highlight particular themes from the Settings Rule and corresponding regulatory requirements, and why these requirements do not fit the needs of older adults.

Theme: Requirements Around Community Integration

One of the key goals of the Settings Rule is community integration. What is ironic about its implementation is that some of these requirements are *decreasing* community integration for older adults, particularly those with dementia. It is causing a significant burden on older adults and those who care for them as well as the provider organizations that serve them. The portion of the Settings Rule related to outings has proven an area of extreme difficulty. From the perspective of LeadingAge providers, program participants, and family caregivers, the trip to the day center *is the outing.*

Many of these programs serve a high proportion of participants with dementia for whom routine is very important in maintaining comfort and trust. Outings can be offered to these participants but requiring providers to schedule transportation and staff support for outings that no participants select to use is not a judicious allocation of resources, especially in the Medicaid program. Similarly, asking that older adults—especially those with cognitive impairments—be coached on employment and volunteer-seeking activities is incongruous with the purpose of these services. There should not be an expectation that individuals who long ago decided to end their working years and started collecting Social Security should need or want to work. Requirements to offer opportunities to work or volunteer in the community to comply with community integration should not come above person-centered planning. Older individuals with dementia that has advanced to a need for adult day or assisted living are not hoping their provider will tutor them in job seeking; these beneficiaries have already held jobs, worked long careers, and are seeking appropriate and compassionate services in safe and effective settings.

1. **Settings Rule Requirement: HCBS Providers Must Support Full Integration Into the Community Including Field Trips and Outings**

   Adult day services providers have been tasked with ensuring integration into the community by providing outings and field trips for participants. The adult day setting, by virtue of how the service is provided to the older adult population, is a functionally integrated community setting in nearly all cases. For the majority of providers, space is either owned or rented in a storefront, standalone building, or church basement. Participants arrive at the center after a bus ride where they have been picked up at their home. In many cases, an aide leaves the bus to enter the home and helps the person get ready and board the bus. Some participants ride the bus for multiple hours to arrive at the day center for their socialization and activities.

These participants attend the center to get out of their homes, interact with their peers at the center, and engage in planned activities. For individuals with dementia diagnoses being served in these settings, consistency of routine and location optimizes their stability and promotes well-being. These paradigms of routine and activity timing are detailed by the government's own Alzheimer's landing page[4] and the Mayo Clinic[5] as options to consider when caring for individuals with dementia. Changes to routine can cause behavioral unrest and can be exhausting for the individual while straining the staff and caregivers attending to the person's needs.[6] Person-centered care planning and the day-to-day administration of care for individuals with dementia is an evolving and flexible process that cannot and should not be overly prescriptive.

Furthermore, workforce shortages remain in all sectors but are particularly acute in health and aging services, where providers can't reduce capacity day-to-day or close early because of staffing shortages. Allocating staff to outings that are subsequently canceled because all participants have opted out reduces hours for staff and may induce their search for more stable hours and income. One member noted that their adult day regulations require a registered nurse to be present at all times. Should the nurse go on the field trip? Should the adult day have to hire a second nurse to staff a trip? Given the fiscal and workforce restraints, that would not be possible. Additionally, how do we consider requirements for a nurse escort to all activities beyond the day center to be person-centered? How does a provider balance their responsibilities for keeping a participant safe, with person-centered care and services, with respect for autonomy, while continuing to comply with integration requirements?

For rural providers, we have also heard questions about where to go. For one member, the only place in close proximity to the center is a Dollar Tree store. They have done outings there, but many participants cannot afford to spend money there or do not have access to money because of their cognitive status. It has fallen to the Center's staff to pay for things when a participant either forgets their wallet or doesn't have funds for checkout. Another provider noted concern that group outings are considered to meet requirements for community integration. What types and specific activities does CMS believe are most appropriate for individuals to be offered? How will participants with fixed or limited incomes after covering cost-sharing requirements pay for these activities? Adult day centers work hard to create socialization and activities within the centers themselves. Participants paint and do woodwork and sing and dance and garden with the support of trained staff—in some cases, staff who are community artists or musicians. Why is a trip to a mall considered to be more community-integrated?

Members have noted changes to their outings policies. Now, if participants need one-on-one support for community outings, a caregiver must accompany the participant on the outing. The caregiver must also pay any costs associated with attending the outing, such as transportation, entry fees, or provided meals. For adult day participants, their attendance at the day center,

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[4] Accessed 4/11/23: https://www.alzheimers.gov/life-with-dementia/tips-caregivers

[5] Accessed 4/11/23: https://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/alzheimers-caregiver/art-20047577

[6] Accessed 6/16/2023: https://www.alz.org/help-support/caregiving/daily-care/daily-care-plan
https://alzheimersproject.org/the-importance-of-routine-and-familiarity-to-persons-with-dementia/

many times, offers their primary caregiver respite from caregiving. This time away allows the caregiver to work in their communities or attend to chores and errands necessary to maintain a household, such as laundry, grocery shopping, or banking. Without the continued support of a community caregiver, many of the participants in adult day settings would be required to move into a nursing home—which is not the Settings Rule's intention of better-integrating recipients of HCBS into their communities.

2. **Settings Rule Requirement: HCBS Settings Must Provide Opportunities to Seek Employment and Work in Competitive and Integrated Settings**

   The vast majority of older individuals who qualify for Medicaid home and community-based services and seek or are using adult day or assisted living services are not looking for employment at this point in their lives. Their working years are behind them.

   Some providers of adult day services for older adults specializing in services to individuals with dementia have reported compliance challenges. Their states have indicated necessary changes to policy to ensure the person-centered service plan offers all recipients of Medicaid-funded home and community-based services access to employment-seeking services. Staff must now ask their participants about their desire to have assistance with job seeking and document the discussion in the person's plan of care. This is the antithesis of person-centered planning. It is confusing, upsetting, and burdensome, particularly for those experiencing cognitive decline or dementia. The person-centered planning process has become more about the requirements of the plan and the process for its development than about the person that was intended to be at the center of the process.

   Aging services providers who serve older people with long-term care needs can comply with this requirement—but why? Having a rule on the books that does not apply to almost everyone being served does not make sense and takes valuable staff time away from beneficiaries.

Theme: Requirements Around Physical Environment That Do Not Make Sense for Older Adults

A number of the requirements of the Settings Rule center around making the physical environment in which services are provided more "homelike." This includes requirements for lockable sleeping units and the ability of residents to decorate their living spaces. Some of these physical requirements are achievable; it is a question of whether making these changes is the best use of Medicaid dollars when there are potentially other avenues for achieving the same goal. In other cases, the physical requirement is inappropriate for the population.

1. **Settings Rule Requirement: Beneficiaries Must Have Privacy in their Sleeping or Living Unit**

   Medicaid reimbursement rates for assisted living range from less than $25 to more than $210 per day. Medicaid is prohibited from paying room and board in community-based settings, meaning

shelter costs are not included in Medicaid rates. Because of requirements for Medicaid programs to be responsible stewards of taxpayer funding, programs have attempted to strike a balance of privacy of residents with judicious reimbursements. Providers offer residents shared rooms with another participant to keep costs closer to rates paid by Medicaid programs. Single rooms are more costly to operate in housekeeping, maintenance, new construction, and climate control. Medicaid rates consistently fall below the actual costs to provider care, causing losses that providers must make up in other business lines or through other payers.

2. **Settings Rule Requirement: Beneficiaries Must Have Access to a Kitchen**

   Access to kitchens has been noted as a pain point by some assisted living providers. Some compliance officers deem the industrial kitchen for the entire building to be accessible to residents, dependent upon their resident agreement. Industrial kitchens in residential communities were never intended to be accessible to residents. Our members cite concerns about resident safety, food safety, and hygiene. Providers must operate their commercial kitchens in alignment with hygiene and food safety requirements imposed on restaurants. Unrestricted access to food or snacks does not require access to a commercial kitchen at all hours of the day. An alternative could easily be a situation where snacks and related options are available freely with the availability to contact a staff person for items that require refrigeration or warming.

3. **Settings Rule Requirement: Beneficiaries Must be Able to Secure Their Space and Belongings**

   With approximately 40% of residents in assisted living facilities having diagnosed dementia, lockable doors are unnecessary. If the provision is intended to increase independence and privacy, staff would maintain master keys for all units to ensure safety and monitor well-being. Maintaining independence for individuals with dementia includes programming and intentional design features to help residents identify their own living units. For a resident with dementia, inadvertently locking their own door would result in frustration and confusion and not improve their person-centered experience.

   Requirements that individuals within assisted living residences have lockable doors for privacy do not apply cleanly for individuals with dementia. Dementia-friendly services undertake extensive efforts to improve the resident experience by assisting residents in remembering where their living space is, limiting dead ends within the unit, and using dynamic lighting to support normal circadian rhythms. How does a lockable door make sense for an individual with dementia who needs to remember a code or key to gain access to their living space?

   The Settings Rule contains provisions that require providers to offer space where participants can secure their belongings. This has been interpreted to mean that a dementia-focused adult day services provider needed to install lockers. How are individuals with dementia expected to remember locker combinations or where they've stowed keys to access their belongings at the end of the day?

Theme: Requirements Around Separation from Other Types of Settings

1. **Setting Rule Requirement: HCBS Settings Must Provide Conflict Free Case Management**

   The Settings Rule's intent for optimal service delivery by eliminating conflict of interest between service provision and case management and service planning is a common-sense check and balance for the Medicaid program. Medicaid programs should not pay for unnecessary services because the provider responsible for developing service authorizations stands to benefit and be reimbursed for padded service plans and extra services.

   However, one of the hallmarks of assisted living is case management. Assisted living is typically reimbursed as an inclusive service that includes a case management component. Adding a requirement that the state impose and cover an additional level of conflict-free case management where the service planner and authorizer is separate and apart from the provider creates an unnecessary and expensive administrative layer for the state. Medicaid beneficiaries are more likely to have a lifetime worth of experiences of difficulty accessing services and mistrust of the medical system. Creating another entity with whom they are expected to form a trusting relationship, when they likely already have a relationship with their assisted living provider for case management, is another layer of bureaucracy that is unnecessary in the older adult population. Assisted living providers are licensed and monitored at the state level for compliance with safety and licensure regulatory frameworks. Providers receiving payment for an inclusive rate will not benefit from providing additional services and are mandated to provide minimum services to meet a resident's needs.

2. **Setting Rule Requirement: HCBS Cannot Share Staff**

   The Settings Rule prohibits sharing of staff between HCBS and institutional settings. Even if sufficient staff were available (and in the current environment, they are not), there are good reasons that direct care staff could be successfully shared between a nursing facility and an adjacent adult day care or assisted living facility. These could include limited consultation on clinically complex individuals, activities support, or crossing over for quick support. High-quality providers could execute this while optimizing participant well-being and staff satisfaction but are not given the opportunity to demonstrate this is possible—even in this moment when such arrangements are likely imperative to being able to provide services at all.

   This prohibition makes even less sense with regard to back-office functions. For roles like human resources, finance, and procurement, streamlining functions into a single administrative office for affiliated providers limits Medicaid waste and allows providers to survive. Eliminating duplicative training, similar task execution, and allowing bulk purchasing minimizes administrative costs. This should be applauded in the Medicaid program, not prohibited.

RECOMMENDATIONS

LeadingAge members are committed to the people they serve, are mission-driven, and strive to provide the highest-quality and most desirable services for the older adults they serve. Our members support the intent of the Settings Rule. The reality remains that the Settings Rule does not fit older adults. We recommend that CMS take the following steps to ensure that the rights of older adults who use Medicaid long-term services and supports be protected in a way that fits the population being served.

1. **Immediately place a two-year moratorium on Settings Rule compliance for adult day and assisted living providers who serve a population primarily over the age of 55 and individuals under age 55 with dementia.** This gives CMS time to develop specific guidance and compliance requirements for these providers. (Note: age 55 aligns with PACE eligibility.)

2. **Over the two-year period, develop compliance guidance specific to aging services.** At a minimum, a review of community integration for individuals with dementia should not require notes in the care plan that the person has been offered job-seeking services; it should not require mention of limitations on "unrestricted access to food" if the individual requires mechanically altered meals or is at high risk of choking. Better understanding of the person isn't optimized through care planning but through careful, diligent, and compassionate interactions with each individual.

3. **If, in developing the guidance, it becomes clear that new rulemaking is needed, extend the moratorium to account for the time needed for the rulemaking process. Ensure that the new rule protects the rights of older individuals who use Medicaid long-term services and supports while respecting that their needs are different from those of working-age individuals.**

    a. Convene aging experts to review the Settings Rule, including those with expertise in aging services, the characteristics of older LTSS users, and the HHS-led Advisory Council on Alzheimer's Research, Care, and Services. Include providers and state officials in the review.

    b. Ensure that the Settings Rule allows for a fluid transition from one setting to another and one service intensity to another. The black-and-white definitions of institutional in opposition to HCBS services don't promote the person-centeredness of experience occurring on a continuum of intensity.

CONCLUSION

By better defining parameters for compliance in settings where the Settings Rule doesn't fit the population being served, Settings Rule compliance efforts can focus more directly on services to individuals for which the Rule was intended. Continuing to review aging services under the same

compliance structure as providers serving working-aged individuals with physical and intellectual/developmental disabilities is diluting the effect and not serving the intended purpose.

Application of the Rule to settings where seniors are receiving services will have a chilling effect on providers' ongoing ability to offer Medicaid-funded HCBS services. Additional costs for staffing to complete lengthy person-centered service planning templates with inapplicable questions coupled with renovations and policy changes do not make financial sense in a system already struggling with low Medicaid reimbursement rates and a staffing crisis. These pressures have pushed and will push providers out of the Medicaid provider space, further limiting options for low-income older adults and forcing more individuals to go without care or pushing them into their only remaining option—a nursing home—quite the opposite of the intent of the Settings Rule.