



NTG Commentary on the CMS 'Settings Rule' and Applications for Housing Adults with Intellectual Disability Living with Dementia

April 2023

Summary

This advisory addresses an issue that many community-based organizations may encounter when state officials must attest as to whether "heightened scrutiny" is needed to determine whether small dementia-capable group homes should be included in their HCBS waivers.

Given the emphasis of the HCBS Settings Rule on community involvement, person-centered planning, and supports that encourage autonomy and well-being, we propose that adults with intellectual disability living with dementia are as entitled to the same kind of experiences funded by HCBS under the provisions of the Settings Rule as other adults not experiencing dementia.

We contend that supporting specialized services for adults with intellectual disability living with dementia in group homes is in the spirit of both the Americans with Disabilities Act, as amended, and the Olmstead Decision, as it provides for safe housing in a least restrictive setting in the community, with specialized services that are appropriate to meet the needs of individuals with progressively diminishing cognitive and functional abilities.

We believe that recognition should be given to small dementia-capable group home settings as a proven best practice support model, which upholds the rights of adults with dementia to live in the community under HCBS waivers funded by the health and social service systems in each state. When properly funded, these settings can provide personalized care, promote well-being and safety from harm, give attention to changing nutritional and dietary needs, and engage residents in activities that mitigate memory loss and cognitive decline. Further, such settings provide adults with intellectual disability living with dementia with both an environment for socialization and one that can attend to deteriorating personal care skills. All this is possible due to the special expertise they have and their ability to provide advanced dementia and end-of-life care.

Additionally, we also believe that recognition should be given to the advantages of small dementia-capable group homes when compared to the costs and outcomes of services that are provided in nursing facilities, because dementia-capable group homes are both less expensive on a per diem basis and more effective in enhancing the quality of life for individuals living with dementia.

Therefore, we propose that CMS should provide guidance to state Medicaid Directors on appropriate program design and rate setting for specialized services in dementia-capable group home settings. Further, we propose that ACL should encourage the mechanisms for standardized training of personnel employed in these home, create guidance for standards for dementia care in such homes, and engage in the provision of technical assistance for the expansion of the use of such homes.

Some History

What follows is a brief explainer and historical look-back at the derivation of public policy that is currently driving a human rights approach to equity and provision of supports for community living by persons with lifelong cognitive impairments, in particular those adults with intellectual disability.

During the 1970s when the country was pursuing active deinstitutionalization efforts, that is moving large segments of people with intellectual disabilities who were institutionalized in large public (and private) congregate facilities over the previous 50 years, into a variety of community settings, the legal basis for rights to choose living settings was absent. Until the advent of federal initiatives to reduce institutional populations and have such settings abide by core standards, the general community was relatively unresponsive to such efforts. As advocates pushed states to comply and to honor basic human rights, the 'normalization' philosophy took hold – one that honored people with disabilities as having a place in their community and to be given the opportunity to live normal lives. 'Communitization,' as a movement followed, which strengthened the push for more opportunities to live out the lives of then institutionalized and previously institutionalized adults within community settings. Absent back in the 1970s and 1980s were housing concerns in the intellectual disability system about aging adults and those who may have become affected by dementia.

Nonetheless, meaningful change did occur. Public beliefs were changed, state agency administrators listened to families and began the shift from an institutional focus on care to one that offered assorted opportunities within the community. This was helped by, among other events, incentives in funding to the states that sought to move state policies toward alternatives. One major alternative was the use of group homes, as these offered small safe settings for transitioning from institutions to community living. The number grew, and some offered specialized care for adults with particular conditions or challenges.¹ In 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constituted discrimination in violation of title II of the Americans with Disabilities Act and opened more opportunities for living in settings of choice. As the new millennium arrived, such small group living became less prevalent as federal and state funding was justifiably directed toward personalized autonomous or supportive living, and many states moved away from funding small group homes.

Yet, while this policy shift served well most adults who were interested and capable of living in other settings, it set in motion a transition within some provider agencies to use these homes to provide community housing for particularly 'vulnerable and dependent' groups, including aging adults and adults living with dementia. These 'new' dementia capable settings provided a viable in-community housing model as they drew upon housing that was available, residents who were already eligible for state-supported services, a readily available funding source (both Medicaid and state appropriated funds) covering most operational costs and followed a model for in-community care.

¹ When enacted Medicaid was the medical care extension of Federally-funded programs providing cash assistance for families with low incomes, with an emphasis on dependent children and their mothers, elderly persons, and persons with disabilities. From its beginnings as a health care financing program primarily for welfare recipients, the Medicaid program has been amended and expanded to cover a wide range of populations and services. In 1981, the Medicaid statute was amended to incorporate provisions that authorized HCBS. [<https://aspe.hhs.gov/reports/understanding-medicaid-home-community-services-primer-2010-edition-0>]

Part of this emanated from the knowledge of the limited alternatives for non-institutional care for adults with moderate to severe dementia. In general, such care options were (and still are) limited to admission to skilled nursing facilities (perhaps to special dementia care units), hospitalization, or continued care by family members or unpaid caregivers. Private 'memory care' or assistive living care, becoming increasingly prevalent, was usually not a viable option due to admission criteria and the costs associated with such care (generally not covered by Medicaid or private insurance). Small dementia care homes, thus, appeared to be an ideal solution in the intellectual and developmental disabilities system as there was a philosophical commitment to lifetime support, a worker base familiar with the nature of intellectual or developmental disabilities, and an existing funding stream for such housing. Interestingly, it is a model that is used in many countries with respect to the general population where such support is covered by health care payment schemes (as in the Netherlands), or investment in dementia community care by the national government (as in Japan and Sweden).² In the US, this type of care and funding for the general population is absent but does exist for historical reasons within the states for adults with intellectual disability.³

Provider agencies that work to setting up such dementia capable care homes often run into several challenges. One is meeting the definitions for a community setting as defined by CMS's Settings Rule; another is securing the level of funding necessary to provide appropriate care and supports as states mostly do not have reimbursement levels established to accommodate dementia care. Also often challenging is assuring that training and clinical supports are provided to ensure a dementia-capable setting and maintaining acceptable person-centered and personalized 'dementia care plans.'

The aim of this advisory is to examine the nature of the Settings Rule and its applicability to providing community-based most inclusive ('least restrictive') dementia care and proffer recommendations for creating equity in access and for the components of care structures and supports across the United States.

The Setting Rule and Dementia

What follows is a backgrounder on some exchanges between CMS and various constituencies related to its initial presentation of the Home & Community Based Services Final Regulations which include the Settings Rule. We have included these discussions to set the framework and to help better understand the nuanced factors and how the housing of adults living with dementia is affected by the regulations. This section also explores the relationship between the Settings Rule and the use of small dementia capable housing settings for adults living with dementia, in particular those adults with intellectual disability.

Section 1115 demonstrations and waiver authorities in section 1915 of the Social Security Act are vehicles that states can use to assess new or existing ways to deliver and pay for health care

² Janicki, M.P., Dalton, A.J., McCallion, P., Davies Baxley, D. & Zendell, A. (2005). Group home care for adults with intellectual disabilities and Alzheimer's disease. *Dementia - The International Journal of Social Research and Practice*, 4(3), 361-385.

³ Kolanowski, A., Fortinsky, R. H., Calkins, M., Devanand, D. P., Gould, E., Heller, T., Hodgson, N. A., Kales, H. C., Kaye, J., Lyketsos, C., Resnick, B., Schicker, M., & Zimmerman, S. (2018). Advancing research on care needs and supportive approaches for persons with dementia: recommendations and rationale. *Journal of the American Medical Directors Association*, 19(12), 1047–1053. <https://doi.org/10.1016/j.jamda.2018.07.005>

services. We recognize that hardly any states have specifically considered persons with dementia in their state plans where the CMS Setting Rule may apply to provide intent to provide community-based residential services. However, 29 state waivers have designated adults with intellectual and developmental disabilities as a focal population in their state⁴, and given the increasing number of older adults with intellectual and developmental disabilities the challenge of providing community-based housing is becoming a more prominent need. Thus, this advisory is directed toward those areas where dementia-capable living is an issue with respect to being considered non-institutional and meeting the HCBS needs of a growing segment of the adults with intellectual disabilities.

The Center for Medicaid and Medicare Services (CMS) has, to its credit, created the framework for ensuring that persons with intellectual and other developmental disabilities find housing in settings of their choice and appropriate to their needs and are not isolated from the greater community (see: Final Regulation CMS-2249-C/CMS-2296-F).^{5,6} The basis for this is the Americans with Disabilities Act, as amended (PL 110-325)⁷ and the Olmstead Decision (Olmstead v. LC)⁸. The CMS set the parameters for the use of Medicaid funds in housing via its 2014 announcement in the Federal Register.⁹ What has become known as the Settings Rule was necessary to standardize definitions of community-based living as some Medicaid providers described their programs as “community-based” but still enforce restrictions on how a person can define their personal spaces, when they can access food, and who can visit them in their home.¹⁰ The Settings Rule adds specific requirements to ensure integrated settings were truly community-based and that any settings receiving Medicaid HCBS funds must ensure participants have choices about their daily lives, their supports are person-centered, and they can participate in the community in ways that reflect their individual interests.

According to the Administration on Community Living¹¹, a ‘setting’ that is truly home and community-based is one that:

- Is integrated in and supports access to the greater community.

⁴ Medicaid.gov (2023). State waivers list. https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html?search_api_fulltext=intellectual+disability&items_per_page=10#content

⁵ Medicaid.gov. (2023). Home & Community Based Services Final Regulation. <https://www.medicaid.gov/medicaid/home-community-based-services/guidance/home-community-based-services-final-regulation/index.html>

⁶ Larson, S.A., Hallas-Muchow, L., Aiken, F., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2016). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2013. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living.

⁷ ADA.gov. Americans with Disabilities Act of 1990, as amended. (2023). <https://www.ada.gov/law-and-regs/ada/>

⁸ Olmstead Rights. Olmstead v. LC: History and Current Status. (2023). <https://www.olmsteadrights.org/about-olmstead/>

⁹ Federal Register / Vol. 79, No. 11 / Thursday, January 16, 2014 / Rules and Regulations. Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers. CMS. Final Regulation CMS-2249-C/CMS-2296-F

¹⁰ NCD. (2022). Strengthening the HCBS Ecosystem: Responding to Dangers of Congregate Settings during COVID-19. <https://ncd.gov/publications/2022/strengthening-hcbs-ecosystem>

¹¹ ACL. (n.d.) HCBS Settings Rule. <https://acl.gov/programs/hcbs-settings-rule>

- Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources.
- Ensures the individual receives services in the community to the same degree of access as individuals not receiving Medicaid home and community-based services.
- 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.
- Person-centered service plans document the options based on the individual's needs, preferences, and for residential settings, the individual's resources.
- Ensures an individual's rights of privacy, dignity, respect, and freedom from coercion and restraint.
- Optimizes individual initiative, autonomy, and independence in making life choices.
- Facilitates individual choice regarding services and supports, and who provides them.

Various organizations raised questions about the nature of certain settings as whether they may be in compliance with the Settings Rule, including housing settings as diverse as farmsteads, co-located housing, gated-communities, and residential schools.¹² CMS notes that some of these types of housing may have 'institutional qualities' and have the effect of isolating adults receiving HCBS from the broader community. However, CMS has permitted accommodations by states that have undertaken a 'heighten scrutiny process' which involves input from the public that the setting meets the qualities of being a home, is community-based, and not have the qualities of an institution.¹³ Issues have also arisen as to how the setting rule facilitates specialty therapeutic housing programs. Included in this specialized housing issue is the provision of personalized community-based dementia care in small group homes.

This last aspect is particularly germane as it furthers the aims of Settings Rule with respect to creating the most viable non-family home support option that accommodates the special support needs associated with dementia, continues to provide in-community housing, permits for personal choice within confines of diminishing cognitive capacities, and is structured around well-being and maintaining personal skills and capabilities. Some settings, such as assisted living facilities and group homes, are subject to additional conditions, because as noted in an advisory issued by Justice in Aging, the provider is a single entity that controls both the individual's housing and services.¹⁴ The Rule allows for modifications of the provider-owned or controlled HCBS settings criteria, as long as these modifications support the needs of the individual and are documented in the person-centered service plan. Key conditions germane to group homes would include that: (a) each individual has privacy in their unit, including choice of roommates and the freedom to furnish and decorate; (b) can control their schedules

¹² On March 22, 2019, the Centers for Medicare and Medicaid Services (CMS) issued new guidance that noted that gated communities, farms, and clustered housing were no longer presumed "segregating." Source: <https://www.psychologytoday.com/us/blog/inspectrum/201903/new-cms-guidance-expands-options-adults-idd>

¹³ CMS. (n.d.) Guidance on settings that have the effect of isolating individuals receiving HCBS from the broader community. <https://www.medicare.gov/medicaid/hcbs/downloads/settings-that-isolate.pdf>

¹⁴ Diamond, H., & Kean, N. (2023 March). The home and community-based services settings rule: A guide for New Jersey Advocates. Justice in Aging. <https://justiceinaging.org/wp-content/uploads/2023/03/HCBS-Settings-Rule-Guide-for-NJ-Advocates.pdf>

and activities, including access to food at any time; (c) can have visitors at any time; and (d) the setting is physically accessible to the individual.

The Rule's vehicle for compliance is the HCBS State Plans which permit each state to define the populations falling under its provisions. States had been given time to obtain waivers to develop transition plans that ensure that the HCBS settings in their state will meet the final rules' requirements.¹⁵ Questions have arisen as how states accommodate the needs of older adults with intellectual disability who are showing additive cognitive decline and are potentially transitioning to dementia. Experts in the field of community-based care have argued for years against the institutionalizing of adults with intellectual disability expressing special needs and with the Olmstead Decision, the Courts ruled that such persons are entitled to reside in settings within the community which provide the least restrictions on their lifestyle and autonomy. Similar arguments have been made that give the availability of a group housing model that meets many of the Settings Rule components that adults with mild cognitive impairment (MCI) and dementia should not face the risk of being institutionalized in large congregate settings, usually skilled nursing facilities or specialized dementia care units simply due to the presence of the diagnosis of dementia.

According to the rule, federal financial participation is enabled if the home and community-based services are provided in settings that focus on the needs of individuals (e.g., persons with intellectual disability) as noted in their person-centered support plan. There are a number of requirements on the services to ensure that they comply with community inclusion (including being integrated and providing support for full access to the greater community; being selected by the individual from among options including non-disability specific settings; ensuring an individual's rights to privacy, dignity, and respect; optimizing individual initiative, autonomy, and independence in making life choices, and facilitating individual choice regarding who provide the services). There are also some conditions related to the settings when owned or controlled by a provider. The onus is on the state plan authority in each state to show that it is complying and to submit a transition plan demonstrating how the compliance will be brought about if not.

In testimony to the federal Advisory Council on Alzheimer's Research, Care, and Services at its April 2016 meeting, the NTG noted that *"We would like to propose that the NTG and other interested parties sit with CMS and collectively develop an interpretative letter for state plan entities for the application of the rules to situations of community housing for people with intellectual disability affected by dementia and would ask the Council to join us in supporting this resolution process."* The testimony went on to note that *"The NTG lauds the efforts of CMS to create a vehicle for system change and provide protections for individuals with disabilities so as to maximize personal choice, decision-making, and community inclusion. However, we find that the rules are silent with respect to optimizing community supports for older persons with disabilities affected by dementia. In the developmental disabilities system in the US, much is being made of trying to preclude (re)institutionalization of adults*

¹⁵ ACL. (2023, Mar 17). Joint statement from the Centers for Medicare & Medicaid Services (CMS) and the Administration on Community Living (ACL): Implementation of the Home and Community-Based Services Settings Regulation. <https://www.medicare.gov/medicaid/home-community-based-services/downloads/hcbs-joint-statement.pdf>

with intellectual disability affected by dementia. We have been informed by many provider organizations and others that as the CMS rules are silent on the application to persons with dementia, they are worried that states may not make independent judgments that maximize community living among adults with dementia in fear of not being compliant with the rules. We have been informed that informal counsel from CMS is that the main vehicle for compliance with respect to dementia is through the artful application of each individual's person-centered support plan. While we support this approach, to get relief it leaves each provider with having to engage their state plan entity to negotiate this process."¹⁶

With respect to guidance on HCBS housing and adults with dementia, the Alzheimer's Association also raised this issue in 2016 in correspondence with CMS.¹⁷ The Association noted the special situations that are presented by dementia, which may require clarification with respect to the Rule's provision for unfettered access to the larger community and right to interact with the community around to the extent that they are able and wish to do. As CMS brought up the issue of wandering, the Association pointed out the need to accommodate wandering can be mitigated by 'controlled egress', as adults with dementia experience 'decline in their other cognitive skills, like judgment and problem solving, creates safety risks" [p.2]. Wandering may lead to being in unfamiliar places and due to cognitive limitations, not recognizing dangerous situations. Even for those adults remaining in their own homes with their families, egress is often controlled, so such 'controls' or restrictions in a group home are not out of norm.

The Association also provided strong evidence of mitigating the impression that such community housing settings are 'settings that isolate.' Much can be made of the individualized nature of support in such settings, as well as focus on meeting other criteria for determining the setting is community-based and provides for the least restrictive characteristics. The provision of individualized person-centered plans for each individual can take into consideration the individual's interests, as well as provide as many options for community involvement as possible.

The Alzheimer's Association proposed that an agency providing housing document the following that shows compliance with the Settings Rule:

- 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, and for travel.
- If a residential setting, residents furnish and decorate their private rooms.
- Staff receive ongoing dementia-specific training.

¹⁶ National Task Group on Intellectual Disabilities and Dementia Practices. (2016). Public Comment to the Federal Advisory Council on Alzheimer's Research, Care, and Services. <https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-advisory-council/napa-advisory-council-meetings/napa-past-meetings/napa-2016-meeting-material/april-2016-comments#MJanicki6>

¹⁷ Alzheimer's Association. Letter from Robert Egge to Michael Nardone, May 20, 2016.

- The setting employs a wide range of programming: small-group activities that help residents socialize around common interests, various 'therapies' 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, multiple common areas, visual cues to orient residents/attendees, and continuous walking paths both indoors and outdoors.

In response, the CMS did proffer an interpretation of the Settings Rule that addressed select concerns raised in the Association's letter, and mainly addressed the 'controlled egress' issues. CMS's FAQ used an explanation of addressing "unsafe wandering or exit-seeking behavior" as a means to back into guidance on providing HCBS group home care for persons with dementia.¹⁸

However, as the NTG proposed in April 2016, to date no specific guidance exists to States on how to accommodate small group homes that provide a HCBS program of services for adults with dementia in general, or more specifically for adults with intellectual disability living with dementia. Using the matter in the December 2016 FAQ, we propose that what follows would be appropriate for accommodating HCBS state plan issue concerning dementia care group homes for persons with intellectual disability.

We contend that supporting special personalized housing for adults with intellectual disability living with dementia is in the spirit of both the Americans with Disabilities Act, as amended, and the Olmstead Decision, as it provides a safe housing setting in the community for individuals with progressively diminishing cognitive and functional abilities and needing both a social care environment for socialization and one that can attend to deteriorating personal care skills. Such settings, while providing personalized care, safety from harm, attention to nutrition and diet, and providing engaging activities that mitigate memory loss and cognitive decline, also generally have special expertise in providing care for advanced dementia and end-of-life.

¹⁸ CMS. (2016, December). FAQs concerning Medicaid Beneficiaries in Home and Community-Based Settings who Exhibit Unsafe Wandering or Exit-Seeking Behavior. <https://www.medicaid.gov/federal-policy-guidance/downloads/faq121516.pdf>

CMS's Evolving Conceptions

What follows is a summary of how CMS's perceptions of providing dementia related housing within the confines of the Home & Community Based Services Final Regulation have evolved and still may benefit from a clearer understanding of the nature of dementia and the existing best practice models within the scope of HCBS and the Settings Rule.

We recognize that CMS has moved toward flexibility on dementia care settings, and in SMD#19-001 (RE: Home and Community-Based Settings Regulation – Heighten Scrutiny; issued March 22, 2019) it proffered that “Promoting community integration for older adults and people with disabilities remains a high priority...” This is promoted through a “heightened scrutiny review that the settings do not have the qualities of an institution and that the settings do have the qualities of home and community-based settings.”¹⁹ In this clarification, the FAQ offers this guidance for dementia care settings:

1. The setting should not be physically located separate and apart from the broader community and does facilitate beneficiary opportunity to access the broader community and participate in community services, consistent with a beneficiary’s person-centered service plan. (FAQ #2).
2. Settings in rural areas are not presumed to be institutional if the residents of the group home have similar access to that of individuals living in the same geographical area (but who are not receiving Medicaid HCBS) to engage in the community. (FAQ #3)

Further, other CMS informal guidance documents provide information on how dementia care homes may be considered as in compliance with the Settings Rule, for example:

1. One document notes that the setting may be “designed specifically for people with disabilities, and often for people with a certain type of disability” (e.g., dementia)²⁰
2. The same document notes that they would include settings where individuals in the setting are primarily or exclusively people with disabilities and on-site staff provide many services to them.²¹

Additionally, CMS in a July 2016 State Operations and Technical Assistance (SOTA) webinar for State Medicaid Agency personnel and the public addressed the topic of “Implementing the HCBS Rules in Settings Serving Individuals with Dementia & Other Cognitive Disabilities” provided some limited insights into dementia care settings.²² The CMS’s Director of the Division of Long Term Services and Supports at the time said that the person-centered plan of care is one of the most important components of the HCBS Settings Rule. He said the person-centered plans of care needs to: (a) Identify

¹⁹ CMS. (2019, March 22). SMD # 19-001; Re: Home and Community-Based Setting Regulation – Heightened Scrutiny. Frequently Asked Questions: HCBS Settings Regulation Implementation – Heightened Scrutiny Reviews of Presumptively Institutional Settings. <https://www.medicaid.gov/federal-policy-guidance/downloads/smd19001.pdf>

²⁰ CMS. (n.d.). Guidance on settings that have the effect of isolating individuals receiving HCBS from the broader community. <https://www.medicaid.gov/medicaid/hcbs/downloads/settings-that-isolate.pdf>

²¹ Ibid.

²² LeadingAge DC. (2016). Implementing the HCBS Rules in Settings Serving Individuals with Dementia & Other Cognitive Disabilities. <https://www.leadingagedc.org/2016/08/03/implementing-the-hcbs-rules-in-settings-serving-individuals-with-dementia-other-cognitive-disabilities/>

the individual's strengths, preferences, needs (clinical and support), and desired outcomes, and (b) include individually identified goals and preferences related to relationships, community participation, employment, income and savings, healthcare and wellness, education, and others. Another aspect of the webinar focused on exit-seeking, thus acknowledging this facet of dementia and dementia care.

CMS's FAQ²³ concerning Medicaid Beneficiaries in Home and Community-Based Settings who Exhibit Unsafe Wandering or Exit-Seeking Behavior (issued on December 15, 2016) discusses unsafe wandering and exit-seeking behaviors. Key take-aways from this FAQ is the importance of a 'person-centered service plan,' or perhaps titled as a 'dementia care plan.' While the introduction to the FAQ notes it is centering on 'service provision for individuals with dementia,' it does not explicitly recognize the nature of dementia but does provide general guidance for settings where wandering and exit-seeking is prevalent (the assumption is that these could be care settings for adults with dementia or severe mental illness). There are provisions for enhancing choice-led involvement in community activities and amenities, but with safety cautions.

The FAQ is somewhat internally contradictory as it recognizes the ways that settings may be designed to accommodate adults with dementia, but also presupposes that many residents have the capacity for normative autonomy and choice and may eventually decide to leave such a setting as "a secured memory unit is no longer necessary to meeting the individual's needs". It also presupposes that the setting should provide "appropriate services in that setting for that person to integrate into the community and exercise greater autonomy, as well as being offered the option of a setting that does not have controlled egress." This appears incongruous, as it would be strange (and perhaps inappropriate) to admit someone to a 'memory unit' in the first place who then develops the capacity to leave and function autonomously. Memory care is seen as an appropriate level of care when progressive decline is associated with diagnosed Alzheimer's disease or dementia.²⁴ As adults are normally admitted to a memory center/program due to progressively diminishing cognitive functioning, 'leaving' a memory center usually involves transitioning to a skilled nursing facility, not moving into a more independent setting.

The safety-related points covered in CMS documents are only a small part of maintaining a safe environment for persons with dementia. The Alzheimer's Association has noted that in addition to wandering, depending on the stage of the disease, functional factors need to be considered, including judgment (e.g., forgetting how to use household appliances), sense of time and place (e.g., getting lost on one's own street), behavior (e.g., becoming easily confused, suspicious or fearful), physical ability (e.g., having trouble with balance), and senses (e.g., experiencing changes in vision, hearing, sensitivity to temperatures or depth perception). Another factor is addressing progressive aging and anticipating significant decline because of transitioning to advanced dementia. With such late-stage progression, safety factors considering supports for non-ambulatory care are primary. The focus is on ensuring that

²³ FAQ: Frequently Asked Questions

²⁴ Castaneda, R., & Sy, P. (2023, Feb 2). Determining when memory care is necessary. *US News and World Report*. <https://health.usnews.com/senior-care/articles/signs-its-time-for-memory-care>

physical care needs are met, and comfort measures are undertaken, and concerns centering on the eventualities of end-of-life care are addressed.²⁵

As do other organizations, the National Institute on Aging provides information on safety via its *Home Safety Checklist for Alzheimer's Disease*.²⁶ Such considerations for creating a dementia-safe environment go far beyond issues of egress or exit-seeking, yet these are not covered in any of the CMS guidances under the Settings Rule. To ensure living safely in the community, these considerations must be addressed and built into any physical and program designs for dementia-capable homes – yet recognized that they do not diminish the nature and character of such homes as being community-based and non-institutional.

Also germane is the trajectory taken from living in a setting that has been home to a setting that provides dementia care. Usually this is a multistep process, beginning with suspicions by staff, family, friends, or others of cognitive decline and memory losses. This usually triggers an interview and assessment with a clinician who may determine the presence of mild cognitive impairment or dementia, after excluding other reasons for cognitive changes. To aid clinicians who may be following up on suspicions or by referral from a primary care physician by undertaking an assessment, CMS issued guidance for cognitive assessment and care plan services and provided a billing code associated with such work (CPT code 99483).²⁷ The process can be used to detect cognitive impairment as part of a routine visit through direct observation or by considering information from the "patient, family, friends, caregivers, and others." CMS suggests that clinicians may also use a brief cognitive test and evaluate health disparities, chronic conditions, and other factors that contribute to increased risk of cognitive impairment. If the clinician detects cognitive impairment at an Annual Wellness Visit (AWV) or other routine visit, he or she may perform a more detailed cognitive assessment and help develop a care plan. For adults with an intellectual disability, it is this plan that may serve as the precursor for the person-centered dementia care plan, which may include housing within a small specialty dementia care group home.

Such pre-admission assessments are important as another feature of the Settings Rule is the provision of choice and participation in a 'person-centered' plan. As the Administration on Community Living (ACL) has noted, "Person-centered service plans document the options based on the individual's needs, preferences, and for residential settings, the individual's resources."²⁸ Such participation is not out of the realm of possibility for adults with intellectual disability living with dementia, particularly those whose dementia may be mild or moderate, and are in the earlier stages of cognitive and physical decline. For these individuals, participation can also involve a process that encourages them to plan for

²⁵ NDSS. (2023). End-of-life and Down syndrome: A companion guidebook to aging and down syndrome: A health and well-being guidebook. https://ndss.org/sites/default/files/2023-03/End_Of_Life_Guidebook_2023_Website_0.pdf?token=mbjndLfH0U0txPhxsnqJEvyCGkVW44DsQuJHYog1SnA

²⁶ National Institute on Aging. (2017). Home safety checklist for Alzheimer's disease. <https://www.nia.nih.gov/health/home-safety-checklist-alzheimers-disease>

²⁷ CMS. (March 31, 2022). Billing and Coding: Cognitive Assessment and Care Plan Service. [https://www.cms.gov/medicare-coverage-](https://www.cms.gov/medicare-coverage-database/view/article.aspx?articleId=59035&ver=3#:~:text=Code%2099483%20provides%20reimbursement%20to,the%20services%20under%20this%20code.)

[database/view/article.aspx?articleId=59035&ver=3#:~:text=Code%2099483%20provides%20reimbursement%20to,the%20services%20under%20this%20code.](https://www.cms.gov/medicare-coverage-database/view/article.aspx?articleId=59035&ver=3#:~:text=Code%2099483%20provides%20reimbursement%20to,the%20services%20under%20this%20code.)

²⁸ ACL. (n.d.) HCBS Settings Rule. <https://acl.gov/programs/hcbs-settings-rule>

the future, by expressing care preferences for advanced care for when their cognitive abilities are compromised – much like having an advance directive. Having personal preferences and expressing them is integral to choice, as is expressing preferences for the future when dementia clouds thought and memory and affects function.

Yet, if these plans are to be effective, they must also contain a level of detail that helps guide the circle of supports (and clinical care services) around an individual with an intellectual disability living with dementia. Dementia care planning is a specialized skill, which may be undertaken by persons on the care team who are insufficiently prepared to envision all of the aspects necessary for dementia care. The reality is that most support coordinators in the intellectual and developmental disabilities system are not adequately trained to write an individually tailored dementia care plan in compliance with CPT code 99483. While the intellectual and developmental system pioneered person-centered planning, the requirement for carefully thought-out dementia care aspects does bear upon the need for more training and educational exposure of such personnel to dementia related issues.

Such plans should also consider managing behavioral and psychological symptoms of dementia (known as BPSDs). BPSDs include a range of neuropsychiatric disturbances such as agitation, aggression, depression, and apathy, among others. The BPSD aspect of a dementia care plan helps staff better understand the nature of behaviors and it includes pragmatic information about how to deal with their expression. Its purpose is to minimize disruptions and adverse effects on other persons in the immediate environment and help mitigate and deescalate occurrences of such behaviors and enhance safety.

An aim of person-centeredness is maximizing wellbeing via valuing the person and his or her uniqueness, understanding and appreciating the person's perspectives, and noting the significance of the person's relationship to his or her social environment.²⁹ As the key ingredients of personalized [or person-centered] planning include (a) participating by expressing wishes and preferences, (2) helping with decisions that affect daily routines, activities, and social experiences, and (3) seeking to maintain function and essential well-being, specialty dementia housing providers can ensure that that these aspects are built into the core program and comply with the person-centered planning constituent of the Settings Rule.

Such plans are also dynamic and reflect incorporating supports associated with changes in function and restrictions as dementia progresses and reflect changing foci from social-oriented supports to personal and physical-oriented supports as germane to advanced dementia. They also need to consider expectations for further cognitive decline, handling BPSDs, maximizing comfort in the environment, and enhancing existing capabilities and skill sets. These plans, thus, should also reflect the rationale for services and supports in the least restrictive alternative within the context of resident capabilities and prognoses for requiring more intensive supports.

²⁹ LINC-AD. (2023, Mar 21). LINC-AD Research Steering Committee Expert Think Tank Meeting – Reconstructing Person-Centeredness. Chapel Hill, North Carolina. <https://alz.org/linc-ad/about.asp>

We contend that there exists a proven in-community model of housing adults with intellectual disability living with dementia that can prevent unwanted and inappropriate admissions to long-term care facilities, either housing other adults with disabilities, or elderly adults who require personal care as they do not have alternative living settings. We propose that small dementia-capable group homes can meet all the regulatory requirements of the Settings Rule, provide for playful person-centered supports, and enable adults to live quality lives with enhanced well-being in a comfortable supportive environment that facilitates choice, involvement, and safety. Beneficial would be acknowledgement or guidance from CMS to the states validating the use of this evidenced-based model and its congruence with the tenets of the Settings Rule.

Commentary

What follows is a brief commentary on what we have covered in the previous sections and our position about the viability of small group homes for in-community dementia supports, noting the availability of education and training resources for enhancing the skills of staff working in such settings, the readily available assessment instruments that can track trajectories and progression of dementia, and the wealth of information on care management practices available for aiding adults with intellectual disability living with dementia to thrive and maintain optimal wellbeing within the realities of what dementia brings with it.

It is difficult to cull out of the various advisories and other documents produced by CMS the explicit acceptance -- notwithstanding the positive motives behind the Settings Rule and its focus on maximizing choice and autonomy -- that the rationale that these motives were not intended to apply to adults with notable dependencies due to being diagnosed with a form of dementia. However, going full circle back to the deinstitutionalization movement of the 70s and 80s and the various legal and legislative directives since then, it is incongruous that the Settings Rule would become an obstacle to the continued community living (least restrictive) opportunities of adults with intellectual disability living with dementia.

The alternatives (such as institutionalization in long-term care settings), save for residing with family, are untenable and certainly not in the spirit of the Olmstead Decision and public policy commitment to community living. Living alone with diminishing capacity and being at risk of self-neglect, abuse, and compromised safety is not acceptable. No one would like to see adults whose lived experience has been in the community, relegated to living out their older age in an institutional setting. While the CMS has not explicitly noted the encouragement of dementia care housing in community settings, it must be assumed that implicit in the language of the various guidances and FAQs is the message that small neighborhood-based dementia capable group homes are a viable alternative for

providing a least restrictive safe zone for adults with ever-increasing diminished cognitive capacities and self-care skills.

We would posit that it is evident that specialty dementia care group homes may be the least restrictive alternative for those adults who are not living in a family home or in a support program that can accommodate the personal care needs of an individual living with dementia while at the same time does not pose undue restrictions on the other residents (such as restricting egress). Such homes can organize a social and physical environment that provides for safety, risk management, and mitigating self-neglect. With proper planning and administrative support, such living settings can function to aid adults living with dementia sustain a quality life experience in their older years. Further, as no state is prevented from designing such a program or targeting adults with intellectual disability living with dementia, these settings should be made available.

A key component, however, must be the demonstration of proficiency of the home's management to provide appropriate and quality dementia supports that promote well-being, retention of skills and function, and provide a living environment that facilitates individual choice within the context of managing a brain disease. Also, a complementary key component is the maintenance of an individualized person-centered plan that involves the individual to the greatest extent possible and is consistent with other aspects of the person's life (and in concert with any plans of the care coordinator or manager).

The intellectual disabilities field has produced a wealth of knowledge related to the identification of cognitive decline in older age among adults with intellectual disability, including screening and assessment instruments that can be used by staff in group home settings.³⁰ Also, available is a national curriculum on dementia and intellectual disabilities produced by the National Task Group, as well as other educational materials stemming from the work of experts across the United States.³¹ Work of the National Alliance of Direct Support Professionals, the primary care staff working in group home settings, is available to provide for e-Badges in dementia and intellectual disability which enable staff to show proficiencies in care practices.³² Similarly, trainings by various Geriatric Workforce Enhancement Programs, at a number of universities across the country or via ECHO media³³, and underwritten by the US Health Resources and Services Administration, are available for providers and their personnel.³⁴ Quality measures also have been defined and providers can seek national certification (e.g., CARF) or comply with state quality standards and regulations for small group homes.

³⁰ National Task Group. (2023). NTG - Early Detection and Screen for Dementia. <https://www.the-ntg.org/ntg-edsd>

³¹ National Task Group. (2023). NTG National Model Training Curriculum on ID and Dementia. <https://www.the-ntg.org/training>

³² National Alliance of Direct Support Professionals. (2023). The NADSP E-Badge Academy. <https://nadsp.org/services/the-nadsp-e-badge-academy/>

³³ Clark, P.G., Ansello, E.F., Helm, F., & Tanzer, R. (2023). Growing older with intellectual and developmental disabilities: implementing and evaluating a project ECHO for dementia education. *Gerontology & Geriatrics Education*, <https://doi.org/10.1080/02701960.2023.2168269>.

³⁴ Health Resources and Services Administration. (2023). Geriatrics Workforce Enhancement Program. <https://www.hrsa.gov/grants/find-funding/HRSA-19-008>

All told, these factors support the recognition of the use of the group home model for personalized dementia housing and supports for adults with intellectual disability. We suggest that commentary from CMS would go far to enable providers to seek approval from state authorities for such programs and enable arguments to go forth for the creation of screens that would enable funding to flow for specialized dementia capable group homes.

Recommendations

What follows is the position and recommendation of the NTG that there is concordance between the Settings Rule and the provision of in-community specialized dementia care in least restrictive settings, such as small group homes. We posit that such homes can comply with heightened scrutiny, if needed, and can deliver a highly capable program of supports that enriches and facilitates choice, well-being, and maintenance of capabilities to the fullest extent possible. We also propose the content areas for a dementia person-centered care plan and provide a schema of contents that can be followed by providers.

The NTG recommends that providers planning to set up housing via a dementia-capable group home for adults with intellectual disability living with mild cognitive impairment (MCI) or dementia as 'residential rehabilitation' should consider the following if HCBS funds are involved. States and their providers can certainly do so under a state-designed waiver program. To comply with the CMS Setting Rule housing (group homes) that provide dementia supports and personal care, providers must consider the following:

Compliance Factors:

1. The siting of the home should be such that is not considered institutional (that is, being on campus or adjacent to an institution). The siting should be normative and in a community setting that permits involvement of residents in community amenities and activities of their choice. Consider the applications of 'heightened scrutiny' and ensure that the site, program, records, and other factors comply with HCBS regulations for being community-based and that supports are provided with respect to person-centered planning.
2. Staff assigned to the home should receive sufficient training on addressing the needs of adults with dementia, including understanding the dynamics of various dementias, the nature of BPSDs³⁵, skills in communication with persons with impaired cognition and potential sensory impairments, managing exit-seeking and egress, diet and nutritional needs of older adults, handling anxiety and aggression, and enabling and fulfilling an individualized person-centered dementia care plan.

³⁵ BPSDs – Behavioral and psychological symptoms of dementia.

3. Complying with requirements for record keeping of behaviors, incidents, and opportunities to provide for choice and involvement of activities that help maintain skill sets and contribute to individual well-being.
4. Coordinating the dementia plan with the individualized person-centered plan under the aegis of the case manager, so that all facets of the person's life and social environment are considered.

Person-centered Plan Factors:

5. Providing for an individualized person-centered dementia care plan that:
 - a. Involves the resident and draws upon his or her stated choices, wants, personal preferences and lived experiences, and desires for the future.
 - b. Is informed by discussions with family members or other individuals who are important to the residents about key aspects of daily routines and rituals.
 - c. Focuses on an individual's strengths and interests and plans for periodic re-assessment to quantify capabilities.
 - d. Fully provides for involvement in activities within the community as much as possible.
 - e. Outlines the individual's reaction to various communication styles.
 - f. Identifies the individual's favorite things to do and experience during the day, as well as experiences that contribute to a bad day.
 - g. Proposes experiences that the person may enjoy as community engagement.
 - h. Describes and works toward mitigating those factors or characteristics that the individuals would find most isolating or stigmatizing.
 - i. Notes justifications for any restrictions that may be in place (e.g., controlling egress)
 - j. If advanced dementia is present, modifies personal and medical care and other supports accordingly, and anticipates future changing needs.

Clinical Support and Administrative Factors:

6. Providing clinical team supports that aid staff and residents address and mitigate BPSDs and other behavioral expressions stemming from dementia.
7. Providing training and education so that staff are well equipped to understand and address dementia-related behaviors and provide for a positive therapeutic environment.
8. Tracking trajectories of decline and adapting care and supports, as well as monitoring applications of the personalized person-centered plan, accordingly, to ensure compliance with HCBS regulations.

These plan factors are not idiosyncratic to settings for persons with intellectual disability, and reflect general practices related to general dementia-capable settings. However, they are itemized here to help with framing plans by providers of intellectual disability services. A schema of the components of a specialized dementia care plan for adults with intellectual disability living with dementia is found in the Appendix.

Further Recommendations

We recognize that other least restrictive settings exist, such as 'aging in place' within a family home, or with a mate, spouse, or other tenants, and that these are preferred options if supports are provided to caregivers. However, we recognized that this is not always possible when a suitable care environment and willing caregiver are not present. We recognize also that providers may have found that using an 'aging in place' option in one of their supportive living alternatives may not be practical eventually and for various reasons opted to develop and maintain a specialized dementia care group home to provide safe housing for some adults. We further propose that this model of providing dementia supports within a least restrictive community setting has viability and is recognized as a sound alternative to more restrictive care in many countries. The model for providing housing for adults with intellectual disability diagnosed with dementia has taken root in many states, as well as in Canadian provinces and other countries. Therefore, we recommend that the following be undertaken in support of a more extensive use of this model within the United States.

- *First*, although we are not saying the CMS discourages use of this living option, we recommend that CMS be more active in recognizing the value of this community living option for persons who have been diagnosed with a brain disease, such as Alzheimer's (or other causes of dementia) and facilitate its acceptance and use within the United States to the greatest extent possible. We further recommend that CMS specifically acknowledge its use for aiding adults with intellectual disability living with dementia, whose other options for remaining within the community are scant and who are in danger of being (re)institutionalized.
- *Second*, we recommend that States be encouraged to establish reimbursement rates appropriate and applicable to supporting housing in small dementia care group homes, with rates adjusted accordingly to the stage of dementia and degree of personal care needs.
- *Third*, although we recognize that CMS does not 'certify' settings, we recommend that to assure quality, that an independent system of 'certification' be developed and supported that would permit organizations operating such small dementia care group homes to seek reviews that would establish initial and then maintain periodic certification for quality outcomes and appropriateness of care.
- *Fourth*, we recommend that federal agencies (e.g., ACL, HRSA) support a system of training of personnel specifically working in small dementia care group homes, that specifically targets direct support professionals (DSPs) and program managers who aspire to, or work in such settings, and whose certifications for having been trained would be transportable.
- *Fifth*, we recommend that federal agencies (e.g., ACL) support programs providing technical assistance and evaluation of best practices, to enable community-based organizations providing dementia support in such settings to benefit from the best advice and evidence-informed information available.



Suggested Citation

The National Task Group on Intellectual Disabilities and Dementia Practices. (2023, April). NTG Commentary on the CMS 'Settings Rule' and Applications for Housing Adults with Intellectual Disability Living with Dementia. <https://www.the-ntg.org/dementia-guidelines>.

Acknowledgements

The NTG appreciates all of those who helped create this document and without whose expertise and experience this would not have been possible to develop. Special thanks go to Thomas Buckley, Chasity Chamberlin, Thomas Cook, David Cox, Nancy Jokinen, Paul Landers, Dawna Torres Mughal, Molly Nocon, Rick Rader, Mary Sowers, Cheryl White, and others, for their thoughtful comments and suggestions.

Appendix

NTG checklist for components and focus areas of a dementia care plan consistent with Settings Rule prescriptions.

Dementia Care Plan for Adults with Intellectual Disability Living with Dementia



This schema for a dementia care plan presupposes that it is an additional specialized component to an individual's general person-centered plan, which considers personal, social, and health variables.

Plan components		
A. General Plan Focus		
Y/N	1	Plan involves the resident and draws upon his or her stated choices, wants, personal preferences and lived experiences, and desires for the future.
Y/N	2	Plan is informed by discussions with family members or other individuals who are important to the individual about key aspects of daily routines and rituals.
Y/N	3	Plan focuses on an individual's strengths and interests and plans for periodic re-assessment to quantify capabilities.
Y/N	4	Plan includes planned supports and activities that provide for involvement within the community, as much as possible.
B. Behavior/Function Focus		
Y/N	1	Plan builds off from original dementia diagnostic information and subsequent assessments of progression and staging.
Y/N	2	Plan recognizes the type of dementia and its expressions as well as stage with respect to cognitive and physical changes.
Y/N	3	Plan tracks co-incident conditions and considers how they may aggravate behavior and affect physical well-being.
Y/N	4	Plan considers individual's communication abilities and reactions and responses to various communication styles in the setting.
Y/N	5	Plan identifies the individual's favorite things to do and experiences during the day, as well as situations that contribute to a 'bad day'.
Y/N	6	Plan notes and provides for experiences that the person may enjoy as community engagement or use of community amenities.
Y/N	7	Plan describes and works toward mitigating those factors or characteristics that the individual would find most isolating or stigmatizing.
Y/N	8	Plan notes justifications for any restrictions that may be in place (e.g., controlling egress, access to places in home, etc.)
Y/N	9	Plan notes present 'behavioral and psychological symptoms of dementia', and provides strategies for how staff address can them, including noting underlying stimulants and any notable patterns that may aid in mitigation.
C. Long Term Focus		
Y/N	1	Plan provides for an understanding of managing dementia and strategies for changing support functions as dementia progresses.
Y/N	2	Plan considers results of periodic re-assessments undertaken to address changes in functional abilities and notes what compensation measures should be introduced.
Y/N	3	Plan considers progression and when advanced dementia is present, what modifications will be made in personal and medical care and other supports.
Y/N	4	Plan anticipates future changing needs and how setting will address end-of-life care.
Y/N	5	Plan considers the resident's wishes for rituals/celebrations/disposal of possessions after death.

v.3/23a National Task Group on Intellectual Disabilities and Dementia Practices www.the-ntg.org (2023)