

# Just Like Home: An Advocate's Guide for State Transitions Under the New Medicaid HCBS Rules

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#### **About This Guide**

New federal regulations set standards for Medicaid-funded home and community-based services (HCBS) so that those services are only provided in settings that truly are community-based and non-institutional. Under those regulations, each state must develop a transition plan that sets forth how the new regulations are to be implemented in that state.

Consumers and other stakeholders should play an active role in transition plan development. To assist states and stakeholders, this guide identifies relevant issues, discusses the applicable law and CMS guidance, and sets forth options and recommendations.

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#### Introduction

The federal government recently issued regulations that, for the first time, set standards to ensure that Medicaid-funded home and community-based services (HCBS) are provided in settings that are non-institutional in nature. These standards, which took effect in March 2014, apply to residential settings such as houses, apartments, and residential care facilities like assisted living facilities. The standards also apply to non-residential settings such as adult day care programs, and day and work programs for persons with disabilities.

This guide assumes that a reader has a general familiarity with the new regulations. An introduction to the regulations is available in another NSCLC guide, *Just Like Home:*An Advocate's Guide to Consumer Rights in Medicaid HCBS.<sup>1</sup> Information about the regulations also is available from the Centers for Medicare and Medicaid Services (CMS)<sup>2</sup> and the HCBS Advocacy website.<sup>3</sup>

In each state, implementation of the regulations will be directed by a transition

plan to be developed by the state for approval by CMS. The transition plan must detail how the state will operate its HCBS programs in accordance with the new regulations. Each transition plan must be developed with input from the public; at a minimum, a state must post a draft transition plan for a notice-and-comment period of at least 30 days.

If prepared conscientiously, each transition plan should address a multiplicity of important issues. NSCLC has developed this guide to assist state and federal officials, along with stakeholders, to identify and address relevant issues in transition plans.

The new federal regulations offer the promise of greater independence and security for the many persons who depend on HCBS. This promise, however, cannot be fulfilled without proper implementation by the state and federal governments. Consumer advocates and other stakeholders must be diligent in participating in the transition process, pointing out important issues, and advocating for policies that protect consumers' interests.

<sup>1 &</sup>quot;Just Like Home: An Advocate's Guide to Consumer Rights in Medicaid HCBS" is available at www.nsclc. org/wp-content/uploads/2014/04/Advocates-Guide-HCBS-Just-Like-Home-05.06.14-2.pdf.

<sup>2</sup> The CMS Home & Community Based Services website is available at www.medicaid.gov/ Medicaid-CHIP-Program-Information/By-Topics/ Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html.

<sup>3</sup> The HCBS Advocacy website, available at www. hcbsadvocacy.org, is a collaborative project of the Association of University Centers on Disabilities, the National Association of Councils on Developmental Disabilities, and the National Disability Rights Network.

## I. Defining the Excluded Settings<sup>4</sup>

#### A. Settings Automatically Excluded By Federal Regulations

The federal regulations identify four settings that cannot be considered HCBS settings:

- 1. Nursing facility
- 2. Institution for mental diseases
- Intermediate care facility for individuals with intellectual disabilities, and
- 4. Hospital

There is little discretion here for the state or stakeholders: the list is clear, and the settings on the list receive Medicaid funding through non-HCBS funding mechanisms. The transition plan needs to note that these settings are not HCBS settings. The transition plan also should indicate, per CMS guidance, that HCBS nonetheless can be provided to assist a consumer in moving from an institution, and may be provided to a temporarily-hospitalized consumer if the HCBS do not duplicate hospital services.<sup>5</sup>

# B. Presumption that Certain Settings Will Not Be Eligible for HCBS Reimbursement

According to the regulations, CMS presumes certain settings have institutional qualities and, as a result, cannot be considered HCBS settings. A presumption, however, is not the last word. A state can attempt to overcome a presumption. To do so, the state must submit information to CMS that shows that the setting actually does not have institutional qualities and has the qualities of an HCBS setting.

The presumption applies to three categories of settings, because these settings tend to isolate and segregate persons with disabilities:

- 1. Settings that share a building with a facility that provides inpatient institutional treatment.
- 2. Settings that are on the grounds of, or immediately adjacent to, a public institution such as a state psychiatric hospital.
- 3. Settings that have the effect of isolating Medicaid HCBS consumers from the broader community of persons not receiving Medicaid HCBS.

The basic analysis is the same for each of these three categories. The initial issue is isolation, and CMS has concluded that there is a risk of isolation if a consumer is living in a setting from one of the three categories listed above. In settings with such a risk of isolation, HCBS funding will be allowed only if the state can show that the setting does not have institutional qualities and instead has

<sup>4 42</sup> C.F.R. §§ 441.301(c)(5) (HCBS waivers), 441.530(a)(2) (Community First Choice option), 441.710(a)(2) (state-plan HCBS services).

<sup>5 79</sup> Fed. Reg. 2,948, 2,951, 2,954-55, 2,967, 2,971 (Jan. 16, 2014).

HCBS qualities.

This analysis applies equally to settings that are provider-owned or controlled (like a licensed facility), and to those that are not. Specifically, it is not enough for a licensed facility to comply with the standards for provider-owned or controlled settings (see Section III of this guide), because those regulations do not address isolation from, or integration with, the broader community. Instead, they address the consumer's control within the setting, such as the consumer's ability to lock his or her door, or have access to food at any time. Accordingly, to protect consumers from being isolated, the presumption analysis must be followed for both setting types.

CMS has implicitly confirmed that the presumption applies to settings that are provider-owned or controlled, and those that are not. As discussed in more detail later in this guide, CMS has identified certain provider-owned or operated settings — for example, residential schools — as tending to lead to isolation. Thus, provider-owned or controlled settings are not exempted from consideration in the three isolation-related categories listed above.

#### Category 1: Setting that Shares Building with a Facility Providing Inpatient Institutional Treatment

If a setting shares a building with a facility providing inpatient institutional treatment, the setting cannot be considered an HCBS setting unless the state shows that the setting does not have institutional qualities and instead has HCBS qualities. A transition plan should identify these settings and, if HCBS

eligibility is desired, explain how the setting in fact does not have institutional qualities and instead has HCBS qualities.<sup>6</sup>

Thus, it is insufficient for a state to say, without more, that it chooses to make HCBS reimbursement available in settings that share a building with a facility providing inpatient treatment or, in a more detailed fashion, that it chooses to make reimbursement available to settings that share a building with a specific type of inpatient facility (a nursing facility, for example). The federal regulations have established a presumption that such settings can lead to isolation, and a state can overcome that presumption only by demonstrating that the settings do not have institutional qualities and instead have HCBS qualities. The showing must be particularly strong, as the regulations require that CMS evaluate the state's showing with "heightened scrutiny."

Overcoming the Presumption: Determining Whether Setting Does Not Have Institutional Qualities and Instead Has HCBS Qualities

This issue must be addressed in the analysis for each of the three categories. In this guide, it is addressed in more detail within this discussion of the first category; this analysis then is referenced in the subsequent discussions of the second and third categories.

<sup>6</sup> It is not clear in the regulations if having institutional qualities is equivalent to lacking HCBS qualities or, as discussed subsequently, if and how having HCBS qualities is different from simply complying with the regulations.

In developing standards for determining when a setting does not have institutional qualities and instead has HCBS qualities, states and stakeholders should recognize a confusing and arguably circular aspect of the regulations. The issue is whether the requirements for overcoming presumptions should be more stringent than the general HCBS requirements. Under the regulations, an HCBS setting must offer such qualities as privacy, dignity, respect, and autonomy, and (as particularly relevant here) must "support full access of individuals receiving Medicaid HCBS to the greater community." Additionally, if a setting falls into one of the three categories listed above, the setting must clear the additional hurdle of being determined to not have the qualities of institution and instead to have the qualities of HCBS settings. It is not explicit in the regulations how this additional hurdle being found to not have institutional qualities and instead to have HCBS qualities — is any different than being found compliant with the basic HCBS regulations.

As a result, a state and stakeholders enter uncertain terrain when setting standards that a setting must meet to clear itself from a presumption that it has institutional qualities. Given that the standards relate to overcoming a presumption, the standards should be more stringent that those that apply to every HCBS setting: otherwise, the presumption would be meaningless. On the other hand, the "basic" HCBS standards and the overcomingpresumption HCBS standards each can be summarized as the standards for a noninstitutional, HCBS setting. Accordingly, if an overcoming-presumption standard seems like a good mechanism for ensuring a noninstitutional, HCBS setting, a state may be inclined to use that same standard in its

implementation of the basic federal HCBS requirements.

This guide recommends that states and stakeholders resolve this issue by developing overcoming-presumption standards that in fact are more stringent and/or detailed than the basic standards. It makes no sense for an overcoming-presumption standard to be the same test that is applied to every HCBS setting. To make the overcoming-presumption standards particularly meaningful, a focus on isolation prevention may be particularly important, given that the presumption arises from a setting being considered likely isolative.

One helpful resource may be CMS's Exploratory Questions to Assist States in Assessment of Residential Settings, because those exploratory questions delve into more specifics of what might be expected in a non-institutional environment. For example, the Exploratory Questions consider a consumer's access to public transportation, the internet, and information about community activities.

This guide recommends that any standards not just be applied in the initial classification of settings, but be used and enforced on an ongoing basis, to ensure that settings will maintain the appropriate qualities. Evidence that certain settings currently operate in a non-institutional manner cannot predict the future of those settings, or of other types of settings that may be developed.

In most cases, the under-presumption settings will be provider-owned or controlled, and thus already subject to the HCBS regulations that speak to control over schedules and activities, access to visitors, physical accessibility, privacy in the living unit,

and protection from eviction. So, when the transition plan addresses settings from one of the three categories, states and stakeholders should look to develop additional standards to reflect the heightened risk of an institutional character in those settings.

# Category 2: Setting on Grounds of, or Immediately Adjacent to, Public Institution

Analysis of this issue is comparable to the analysis above for facilities that share a building with a facility providing inpatient institutional treatment (category #1). If a setting is on the grounds of, or immediately adjacent to, a public institution, it is presumed to have institutional qualities. A transition plan should identify these settings and, as desired, explain how the setting actually does not have institutional qualities.

This guide recommends that the state, in order to overcome the presumption, should propose standards to ensure non-institutional qualities.

# Category 3: Setting that Has Effect of Isolating Medicaid HCBS Consumers from Broader Community of Persons Not Receiving Medicaid HCBS

Analyzing settings in this category is a twostep process. The first step is to determine whether a setting has the effect of isolating consumers. If the setting does not lead to isolation, then HCBS reimbursement is possible (assuming that other requirements are met). If however, the setting leads to isolation, the second question must be answered — whether the setting has institutional qualities instead of HCBS qualities. When this second step is reached, there is a presumption that the setting has institutional qualities, since the setting has been determined to lead to isolation. If the state argues that HCBS reimbursement nonetheless should be available, the state must make a showing that the setting in fact has HCBS qualities rather than institutional qualities.

In working through this issue, a state should have a clear understanding of settings within the state that have the effect of isolating consumers. In summary, the two basic questions are:

- Does a certain setting or type of setting have the effect of isolating consumers?, and
- 2. Does a certain setting or type of setting have institutional qualities instead of HCBS qualities?

# A. Does Setting Have Effect of Isolating Individuals Receiving HCBS?

#### i. The Law and CMS Guidance

CMS has issued Guidance on Settings that Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community. The CMS Guidance lists two characteristics that, if both are present, may indicate a setting that has the effect of isolating persons:

- The setting is designed specifically for people with disabilities, and often even for people with a certain type of disability.
- The individuals in the setting are primarily or exclusively people with disabilities and

on-site staff provides many services to them.

Also, the CMS guidance lists three additional characteristics that may be markers for settings that have the effect of isolating persons:

- The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities.
- People in the setting have limited, if any, interaction with the broader community.
- Settings use/authorize interventions/ restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion).<sup>7</sup>

Finally, in yet another list in the same Guidance, CMS lists four specific types of settings that generally have the effect of isolating persons receiving HCBS from the broader community:

- Farmstead or Disability-Specific Farm Community
- Gated/Secured "Community" for Persons with Disabilities
- Residential Schools
- Multiple Settings Co-Located and Operationally Related (for example,

numerous group homes in close proximity to each other)

The CMS Guidance notes that continuing care retirement communities (CCRCs) generally do not raise concerns around isolation, "particularly since CCRCs typically include residents who live independently in addition to those who receive HCBS."

## ii. Whether Setting Has Effect of Isolating Individuals Receiving HCBS

As described above, a state must identify those settings that have the effect of isolating HCBS consumers from the broader community of persons not receiving Medicaid HCBS. This guide suggests that states and stakeholders not overthink this question: to a significant degree, the CMS Guidance and its bullet-point lists match the general understanding of the word "isolation." If the setting is set up and operated in such a way that consumers do not have experiences outside the setting, then the setting has the effect of isolating consumers.

Because the federal regulations refer to the isolation of persons "receiving Medicaid HCBS," one question is whether the concept of isolation refers primarily to the isolation of persons with disabilities, or the isolation of persons who are Medicaid-eligible. Based on the Guidance's bullet-point lists, and also on the regulations' reference to isolation from the "broader community," it appears that the proper interpretation is that isolation means the isolation of persons with disabilities.

<sup>7</sup> It is doubtful that this list's third characteristic
— a restriction such as seclusion — is useful in identifying those settings that are presumed to be isolative. As discussed later in this guide, such a restriction would violate a consumer's basic right under the HCBS regulations to be free from coercion and restraint. In other words: no setting with seclusion can qualify as an HCBS setting, so it would be pointless to evaluate such a setting under the presumption framework.

<sup>8</sup> CMS, Guidance on Settings that Have the Effect of Isolating Individuals receiving HCBS from the Broader Community (March 2014), at 3.

Thus, a setting cannot prove compliance by showing that persons receiving HCBS-funded services are integrated with persons receiving differently-funded services. The broader, most important issue is whether persons with disabilities are integrated with persons who do not have disabilities.

This guide suggests that states and stakeholders be conscientious in identifying those settings that tend to isolate consumers. CMS already has identified certain settings that generally lead to isolation – farmsteads, gated/secured communities, and residential schools. CMS also has identified "multiple settings co-located and operationally related" as likely to lead to isolation. In addition, in the release of the regulations, CMS noted that "size can play an important role in whether a setting has institutional qualities and may not be home and communitybased." CMS declined to set a single federal standard as to size, but stated that it "respect[s] a state's right to establish state laws to implement such a requirement regarding size."9

An issue for the state and for stakeholders, then, is determining what level of geographic concentration is unacceptable. For example, the state may adopt standards that indicate isolation if a certain number of settings or HCBS consumers are within a certain radius. Standards may also consider factors such as the number of settings, the number of HCBS consumers, the number of persons with a disability (regardless of reimbursement source), and/or a percentage comparing the number of persons with a disability, to the number of persons without a disability.<sup>10</sup> As

appropriate, these various standards may vary depending on the type of setting — for example, licensed facilities may be treated differently from public housing.

Furthermore, the same type of analysis could be extended to a single large setting. Again, the potential problem is the concentration of a large number of persons, without meaningful interaction with the broader community. Large population settings may be most suspect, particularly when a high percentage of the setting's residents are persons with disabilities.

It is possible that technology may be of assistance in identifying instances of isolation. For example, the lowa work plan for developing a transition plan calls for a Geographic Information System to be used "to analyze potentially isolating locations of provider sites and congregate member living." Of course, such a system would be just one method of identifying isolation, since geographic considerations are only part of the story.

#### iii. Isolation Within Setting

The state and stakeholders may also wish to consider whether HCBS consumers

number of HCBS consumers must not exceed four, or 25% of the total number of units, whichever is greater. Minn. Stat. 256B.492(a)(3). Unsuccessful 2014 legislation would have softened this requirement by allowing an exception for a setting that, among other things, provides and facilitates "unlimited access to the community," and "supports or develops scattered-site alternatives to the setting." Minn. House File 1992 (2014).

11 Iowa Dep't of Human Servs., HCBS Settings: State Home and Community Based Services (HCBS) Setting Transition Plan Due 7/31/2014, at 1.

<sup>9 79</sup> Fed. Reg. at 2,968.

<sup>10</sup> For example, in an HCBS setting in Minnesota, the

within a residential setting are isolated from others who are not receiving HCBS. It can be argued that segregation within a setting is not addressed by the regulations, since the regulations refer to isolation from the "broader community" of persons not receiving Medicaid HCBS. On the other hand, CMS has found that CCRCs are not isolative based on the fact that the CCRC setting includes persons who live independently, which indicates that within-setting conditions are relevant.

This guide encourages states and stakeholders to consider and, as necessary, address this issue. HCBS consumers may be isolated even if a residential setting includes persons without disabilities, if the HCBS consumers have no real contact with them.

## B. Does Setting Have Institutional Qualities Instead of HCBS Qualities?

This is the second step for the analysis of those settings that have the effect of isolating HCBS consumers. Analysis here is comparable to the analysis above for categories # 1 and # 2. A state should develop standards to ensure that a setting does not have institutional qualities and instead has HCBS qualities. There may be some question as to how these standards may differ from the basic HCBS standards; as discussed previously, this guide recommends that those standards focus on the prevention of isolation, because the presumption results from the setting being likely isolative.

Assuming that such a standard were developed, there might be a question as to how it would be applied in category #3 — whether compliance with the standard

would mean that the presumption was overcome, or instead would mean that the presumption never would have developed, since the setting would not be a setting with the effect of isolating HCBS consumers. This guide suggests that compliance with the standard would be best characterized as an overcoming of the presumption, in order to maintain consistency with the analysis for categories # 1 and #2. In any case, the question ultimately would be somewhat academic, as compliance with the standard in either characterization would result in the setting being appropriate (absent any additional problem) for HCBS reimbursement.

# Identifying Settings Disqualified from HCBS for Having Qualities of Institutional Setting

#### **First Step:**

# **Determining Settings Presumed to Have Qualities of Institutional Setting**

Presumption of Institutional Quality in Any of These Three Situations

Analysis Applies Both to Settings that Are Provider-Owned or Controlled, and Those that Are Not



Shares Building with Facility Providing Inpatient Institutional Treatment On Grounds of, or Adjacent to, Public Institution

Isolates Medicaid HCBS
Consumers from Broader
Community of Persons Not
Receiving Medicaid HCBS

Certain Settings Have Already Been Determined by CMS to Be Isolative:

- Farmsteads
- Gated/Secured Communities for People with Disabilities
- Residential Schools
- "Multiple Settings Co-Located and Operationally Related"

Isolative Settings Generally Are:

Designed Specifically for Persons with Disabilities, &

Occupied Almost Exclusively by Service Recipients and Service Providers Other Settings (Including Licensed Facilities) Must Be Evaluated as to Whether They Have the Effect of Isolating HCBS Consumers.

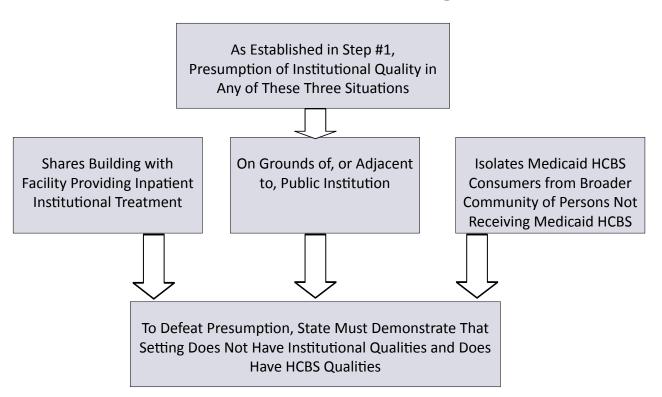
Possible Considerations Include Number and/or Percentage of Persons with Disabilities.

Isolation within Setting May Also Be Consideration, If Setting Has Separation of Persons with Disabilities from Persons Without Disabilities

Setting Might Be Considered Non-Isolative
If It Meets Certain Standards for Ensuring
that Consumers Have Meaningful Contact
with Broader Community

#### **Second Step:**

Evaluating Whether Presumption Has Been Overcome by Showing that Setting Does Not Have Qualities of Institution, and Does Have Qualities of HCBS Setting



Limited CMS Guidance Thus Far on Evidence Necessary to Show That Setting Does Not Have Qualities of Institution and Has Qualities of HCBS Setting Required Evidence Should Be More Than
Anticipation of Future Compliance with HCBS
Regulations, Since These Settings Have to Overcome
Presumption That They Have Institutional Qualities

Possible Confusion as to How Presumption-Overcoming Standards Should Differ from Basic Standards for HCBS Settings

"Extra" Standards to Overcome Presumption Might Focus on Preventing Isolation

# II. ImplementingStandardsApplicable to AllHCBS Settings

The new regulations establish standards that must be met for a setting to be considered an HCBS setting. The steps for implementation of these standards must be set forth in the state's transition plan.

Many of these standards are relatively broad and will need elaboration to be more meaningful. For assistance in fleshing out these broad rights, states and stakeholders can consult CMS's Exploratory Questions to Assist States in Assessment of Residential Settings, as many of those exploratory questions raise issues that are relevant in both residential and non-residential settings. An HCBS Worksheet for Assessing Services and Settings, available at hcbsadvocacy.org, matches CMS guidance with the corresponding regulatory provision. CMS has indicated that guidance for non-residential settings will be forthcoming.

Access to the community is a foundational element of a community setting, and may depend upon the availability of transportation. Based on CMS guidance on settings that isolate, it should not be enough that consumers are "free to leave." Through providing transportation or otherwise, the state and/or providers should have a greater obligation to ensure that access to the

Enforcement of standards is another important issue in making the regulations' protections real for individual consumers. The discussion of enforcement is somewhat complicated by the fact that these standards apply to all types of settings — those that are provider-owned or controlled, and those that are not. A state can assess requirements against HCBS service providers whether or not those service providers also control the consumer's residence, although expectations will be higher for those providers that do control the consumer's residence.

To enforce the law against an HCBS service provider, a Medicaid program could develop an internal mechanism and/or incorporate the relevant regulatory provisions into state licensure rules. States almost always will have preexisting licensure systems for residential facilities (such as assisted living facilities), and sometimes will have such systems for in-home service providers. Particularly for facilities, as discussed in more detail in Section III, this guide suggests that states utilize the licensure-system option, given that licensure systems tend to have preexisting mechanisms for routine inspections, complaint investigations, and imposition of remedies.

Finally, when determining how to assess responsibility for regulatory noncompliance, the state should not overlook possible

community is real and not just theoretical. The obligation of the state or provider may vary to a certain extent with the setting's location and the practical availability of public transportation. Also, because of the many variables, a state's review of the transportation options should not be limited to a paper review.

<sup>12</sup> CMS, Exploratory Questions to Assist States in Assessment of Residential Settings, at 4-5.

inadequacies in HCBS services. Consider, for example, the regulatory requirement that a setting support consumers' access to the community to receive services. In a provider-owned or controlled setting, the consumer's inability to access community services might be attributed to the facility's failure to provide or facilitate transportation but, in any type of setting, the problem might be at least in part the state's failure in its HCBS program to address transportation and access issues.

The following tables summarize the regulatory requirements along with some relevant considerations, questions and recommendations for states and stakeholders:

### **Standards Applicable to All HCBS Settings**

42 C.F.R. §§ 441.301(c)(4), 441.530(a)(1), 441.710(a)(1)

42 C.F.K. 99 441.301(c)(4), 441.530(a)(1), 441.710(a)(1)	
Regulatory Requirements	Considerations/Questions/ Recommendations
Setting must be integrated in greater community.	
Setting must support full access of HCBS consumer to greater community.	Transportation is significant component of this issue. Transportation concerns are discussed generally in introductory material to this table.
Setting must support consumer's access to opportunities to seek employment and work in competitive integrated settings, to same extent as persons not receiving Medicaid HCBS.	Transportation is significant component of this issue.  Supported employment should be first option to consider.  As explained by CMS, support is required only for consumers with interest in seeking employment. <sup>A</sup>
Setting must support consumer's ability to engage in community life, to same extent as persons not receiving Medicaid HCBS.	Transportation is significant component of this issue.
Setting must support consumer's ability to control personal resources, to same extent as persons not receiving Medicaid HCBS.	For example, setting should not require or encourage use of representative payee unless need for such has been demonstrated.

Standards Applicable to	All HCBS Settings (cont.)
Setting must support consumer's ability to receive services in community, to same extent as persons not receiving Medicaid HCBS.	Transportation is significant component of this issue.  This right is related to service-planning requirement (see Section IV) that consumer be given informed choice of service provider.
In choosing setting, consumer must have options of non-disability-specific setting and private unit in residential setting. Setting options must be identified in service plan, and must be based on consumer's needs, preferences, and, for residential settings, resources available for room and board.	To ensure that HCBS consumers are not priced out of private occupancy in provider-owned or controlled settings, this guide recommends that state should limit provider's room and board charges to amount of monthly income available to consumer for room and board under Medicaid eligibility and post-eligibility rules. The "option" of private occupancy is illusory if that option costs more than HCBS consumer will be able to afford under Medicaid income rules.  Also, to ensure that "choice" of shared occupancy is not coerced, state could allow shared occupancy only with family members and friends. Absent coercion, financial or otherwise, there is no reason why consumer would choose to share unit with stranger.  State may wish to develop service-planning template that sets forth housing options for consumer, to ensure that consumer has real options. Data drawn from templates might assist in demonstrating status of housing availability.
Setting must ensure consumer's privacy.	,
Setting must ensure consumer's dignity.	
Setting must ensure consumer's right of respect.	

Standards Applicable to	All HCBS Settings (cont.)
Setting must ensure consumer's right to be free from coercion and restraint.	For example, recent Minnesota legislation provides one a one-year phase-out of aversive or deprivation procedures. Minn. Stat. 245D.06(5), (8). To assist the transition, state has developed technical assistance web page. <sup>B</sup>
Setting must optimize, but not regiment, consumer's individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.	Choice should not be group activity or nothing. CMS explains that consumers "must be afforded choice regarding the activities in which they wish to participate including whether to participate in a group activity or to engage in other activities which may not be pre-planned."
Setting must facilitate individual choice regarding services and supports.	See Section IV for similar requirement in service planning process.
Setting must facilitate individual choice regarding service providers.	One way to monitor is to compare service plans and see if most or all consumers are using same provider.  See Section IV for similar requirement in service planning process.

#### **Table Endnotes**

- A. 79 Fed. Reg. at 2,976.
- B. Minn. Dep't of Human Servs., Positive Supports Community of Practice, available at http://mn.gov/dhs/partners-and-providers/continuing-care/provider-information/positive-support-cop.jsp.
- C. 79 Fed. Reg. at 2,978.

# III. Implementing Standards Applicable to Provider-Owned or Controlled HCBS Settings

The new regulations also establish standards for provider-owned or controlled HCBS settings. In many cases, these settings are licensed facilities such as an assisted living facility. As is the case for implementation of the basic HCBS settings standards (see Section II, above), implementation of the standards for provider-owned or controlled settings must be set forth in the state's transition plan.

Again, states and stakeholders may wish to review CMS's Exploratory Questions to Assist States in Assessment of Residential Settings, and the HCBS Worksheet for Assessing Services and Settings, available at <a href="https://hcbs.dvocacy.org">hcbs.dvocacy.org</a>. These resources may help both states and stakeholders in thinking through implementation of the regulatory standards.

#### A. Enforcing Standards

As is true for the basic HCBS standards, enforcement of the standards for provider-owned or controlled settings is a vitally important issue. Unfortunately, most current HCBS systems have little or no capacity

to protect individual consumer rights and focus instead on a retrospective review of data. Retrospective review, however, is an ineffective remedy for an individual consumer's problem.

This guide recommends that states develop mechanisms to monitor and enforce compliance with the regulations for provider-owned or controlled settings. One possibility is that the state develop that mechanism within the state Medicaid agency; another is for the state to amend its relevant facility licensure standards to incorporate the federal standards. The amendments could apply only to those facilities certified to accept Medicaid or, instead, to all facilities of that licensure type, as the state might choose.

In the opinion of this guide's authors, amendment of licensure standards probably is the best alternative, since the state's licensure structure already should have provisions for periodic inspections, complaint investigations, and assessment of remedies, while the state Medicaid program probably has none of these things. Regardless of which mechanism is chosen, states and stakeholders should be scrupulous in developing a system that monitors compliance and, for individual disputes, provides a consumer with effective remedies.

#### B. Prohibiting Payment-Source Discrimination

This guide also recommends that these standards be applied both to Medicaid recipients and to those consumers whose services are not funded by Medicaid.

Provider-owned or controlled settings generally are licensed facilities — such as an assisted living facilities or an adult residential facilities for persons with disabilities — and the risk is great that they operate in ways that are institutional. Because of that risk, the new HCBS regulations apply additional requirements to those settings. Those regulations must apply to all residents, regardless of payment source, if the facility truly is to be considered non-institutional and thus eligible for reimbursement as a community-based setting.

It is instructive to consider the ramification of a contrary interpretation. In general, the regulations establish five standards specifically for provider-owned or controlled settings:

- A legal right to a specific physical place, with protection against eviction.
- Privacy, including lockable doors and the right to choose a roommate.
- Control of schedules and activities, with access to food at any time.
- Access to visitors at any time.
- Physical accessibility.

If these protections were applied to Medicaid beneficiaries, but denied to other residents, the result would be an institutional environment. Imagine, for example, visitors being allowed for Medicaid beneficiaries but not for other facility residents. This type of payment-source discrimination clearly would be contrary to the goal of a home-like environment and thus harmful to Medicaid beneficiaries.

Consistent with these principles, the regulations for provider-owned or controlled residential settings generally refer broadly

to all residents of the setting — specifically, to "individuals" or to "each individual." <sup>13</sup> Importantly, the regulations generally do not make a distinction based on a resident's payment source, indicating that the standards set by the regulations should apply to all of the setting's residents.

An exception is seen in one specific provision, requiring that a State ensure that a written lease or similar agreement is in place for "each HCBS participant." The limited use of this more restrictive term reinforces the understanding that the term "individual" should include setting residents regardless of their payment source. If the term "individual" instead were interpreted to refer only to persons with Medicaid HCBS reimbursement for services, there would be no need to make a specific reference to an "HCBS participant."

The following tables summarize the regulatory requirements along with some relevant considerations, questions and recommendations for states and stakeholders.

<sup>13 42</sup> C.F.R. §§ 441.301(b)(4)(vi), 441.530(a)(1(vi), 441.710(a)(1)(vi) (HCBS waivers, Community First Choice option, and HCBS state-plan services, respectively).

<sup>14 42</sup> C.F.R. §§ 441.301(b)(4)(vi)(A), 441.530(a) (1(vi)(A), 441.710(a)(1)(vi)(A). In the case of the Community First Choice option, the regulation refers to "each participant" rather than "each HCBS participant."

# Standards Applicable to Provider-Owned or Controlled HCBS Settings

42 C.F.R. §§ 441.301(c)(4)(vi), 441.530(a)(1)(vi), 441.710(a)(1)(vi)

Regulatory Requirements	Considerations/Questions/ Recommendations
Living unit must be specific physical place that can be owned, rented, or occupied by consumer under legally enforceable agreement.	
Consumer must have, at minimum, the same responsibilities and protections from eviction that tenants have under relevant landlord/tenant law.	
If landlord/tenant law otherwise does not apply, state must ensure that each consumer, through lease, residency agreement, or other written agreement, receives comparable protections for eviction processes and appeals.	State may wish to develop a model agreement. That agreement also should document provider's obligation to comply with other HCBS settings requirements.
Consumer must have privacy in sleeping or living unit.	
Consumer's unit must have entrance door lockable by consumer, with only consumer and appropriate staff having keys.	Per CMS, specific staff members with keys do not have to be identified in service plan, but consumer "should have a say and agree with who that person is."
If consumer shares living unit, consumer must have choice of roommate.	State and stakeholders may want to develop roommate finder system or something comparable so that pool of potential roommates is large enough to make choice meaningful.
Consumer must have freedom to furnish and decorate sleeping or living unit, subject to lease or other agreement.	Lease may set reasonable limits as long as limits are not discriminatory and do not deny legal rights. <sup>B</sup>
Consumer must have freedom and support to control own schedule and activities.	Stakeholders should note consumer's affirmative right to support.

Standards Applicable to Provider-Owned or Controlled HCBS Settings (cont.)	
Consumer must have access to food at any time.	Food options should not be unreasonably limited. CMS notes that requirement would not be satisfied by choice between granola bar, or pitcher of water and crackers. <sup>c</sup>
Consumer must have right to have visitor of his or her own choosing at any time.	Visitation overnight must be allowable, subject to limits in lease or other agreement that prevent visitation from being stretched into legal occupancy. D
Setting must be physically accessible.	More specificity needed; transition plan may incorporate pre-existing accessibility standards.
Modification of standards only if supported by assessed need and justified in service plan.	Relevant service plan requirements are discussed in this guide's Section IV.

#### **Table Endnotes**

- A. 79 Fed. Reg. at 2,964.
- B. 79 Fed. Reg. at 2,963.
- C. 79 Fed. Reg. at 2,965-66.
- D. 79 Fed. Reg. at 2,966.

## IV. Implementing Person-Centered Service Planning Regulations

The recently-promulgated HCBS regulations include standards for person-centered service planning for HCBS provided under 1915(c) waivers. Those standards are effective immediately. This guide recommends that a state's transition plan include the state's strategy for implementing these new service planning regulations. Although the transition plan is described in the regulations as a mechanism for implementation of the HCBS settings standards, <sup>15</sup> it would be efficient and beneficial for a transition plan to address both the settings standards and the service planning procedures.

The following tables summarize the regulatory requirements along with some relevant considerations, questions and recommendations for states and stakeholders. The first table addresses the service planning process; the second table addresses service plans.

Person-Centered Planning Process 42 C.F.R. § 441.301(c)(1)	
Regulatory Requirements	Considerations/Questions/ Recommendations
Consumer will lead planning process when possible.	
Consumer's representative should have participatory role, as needed and defined by consumer, "unless State law confers decision-making authority to the legal representative."	This guide recommends that consumer retain significant decision-making authority even if guardian or conservator has been appointed. In states' guardianship/conservatorship laws, consumer generally retains authority over daily decisions and preferences.
Process must include people chosen by consumer.	This guide recommends that process be set up in way that makes this right very clear to consumer.  The consumer has right to decide that person will <i>not</i> participate in planning process. <sup>A</sup>

<sup>15 42</sup> C.F.R. § 441.301(c)(6)(i).

Person-Centered Pla	nning Process (cont.)
Process must provide necessary information and support to ensure that consumer directs process to maximum extent possible.	This guide recommends that state specify what information should be provided to consumer.
Process must be timely.	This guide recommends that state set timelines for service planning process.
Process must occur at times and locations convenient to consumer.	This guide recommends that default be meetings occurring in setting, unless consumer requests otherwise.
Process must reflect consumer's cultural considerations.	
Information must be presented in plain language.	Q: Should state develop standardized service planning template?
Information must be presented in manner accessible to persons with disabilities.	
Information must be presented in manner accessible to persons who are limited English proficient.	If state develops standardized template (see above), state should require that template be translated into languages spoken by more than specified percentage (5%?) of relevant population.
Process must include strategies for conflict resolution, including clear conflict-of-interest guidelines.	This guide recommends that consumer have appeal rights. Otherwise, consumer has insufficient leverage when conflicts arise.
	To make appeal rights clear, this guide recommends that each service plan include clear written notice of appeal rights, and that such notices meet due process requirements.
HCBS service providers (along with employees and related entities) generally must not provide case management or develop service plan.	State may want to be more specific than regulatory language in defining HCBS service providers, employees, and related entities.
	It is important to consider how this issue is addressed in Medicaid managed care systems.

Person-Centered Pla	nning Process (cont.)
HCBS service provider may provide case management or develop service plan if, within geographic region, an HCBS service provider is only qualified entity to provide case management and/or develop service plans. In that case, state must develop, and CMS must approve, conflict of interest protections that include separation of functions within entity.	
Process must offer consumer informed choice of services and supports.	
Process must offer consumer informed choice of service provider.	This guide recommends that consumers be given a written list of potential service providers.
Process must include method for consumer to request plan updates.	This guide recommends that consumer be allowed to request update orally or in writing.  Pursuant to section 441.301(c)(3), plan must be reviewed least every 12 months, when consumer's circumstances or needs have changed significantly, or on consumer's request.
Process must record alternative settings considered by consumer.	

# Person-Centered Service Plan

42 C.F.R. § 441.301(c)(2)

42 C.F.R. § 441.301(c)(2)		
Regulatory Requirements	Considerations/Questions/ Recommendations	
Plan must reflect services and supports necessary to meet assessed needs and address consumer's preferences.	Must include services and supports regardless of funding source, including natural supports provided voluntarily by family or friends.	
Plan must reflect that setting was selected by consumer.	CMS guidance suggests that consumer should be "given opportunities to visit other settings." Video could also be used to provide consumers with information.	
	Another important consideration is whether consumer can be with friends in setting.	
	Issue is addressed further in this guide's Section II.	
Plan must reflect consumer's strengths and preferences.		
Plan must reflect consumer's clinical and support needs, based on assessment of functional need.		
Plan must include consumer's identified goals and desired outcomes.	Goals and desired outcomes must incorporate consumer's preferences, and should not be limited to clinical concerns.	
Plan must reflect services and supports, paid and unpaid, needed to assist consumer in achieving identified goals.		
Plan must reflect paid and unpaid providers of services and supports.		
Plan must reflect individual risk factors.		
Plan must reflect measures in place to minimize risk factors, including back-up plans as necessary.		
Plan must be understandable to consumer.	At minimum, state should test format with groups of consumers.	

Person-Centered S	Service Plan (cont.)
Plan must be understandable to persons	At minimum, state should test format with
important in supporting consumer.	groups of representative persons.
Plan must be written in plain language.	
Plan must be written in manner accessible to persons with disabilities.	State may want to be more specific, for example: Plan must be available in alternative formats, according to the needs of the consumer, including Braille and other alternative media as requested.
Plan must be written in manner accessible to persons who are limited English proficient.	State may want to be more specific about accessibility for LEP individuals. May want to require plan to include access to interpreter, and require plan to be translated into state's threshold languages.
Plan must identify persons and/or entity responsible for monitoring plan.	State may want to be more specific, requiring that the plan identifies person and/or entity that consumer selects to monitor plan.
Consumer must finalize and agree to plan with informed consent in writing.	Important to determine how consumer demonstrates informed consent, and what plan process must include to facilitate informed consent.
All persons responsible for implementing plan must sign it.	
All providers responsible for implementing plan must sign it.	
Plan must be distributed to consumer.	State may want to be more specific to ensure that plan is distributed to consumer in accessible manner and format.
Plan must be distributed to all persons involved in plan.	
Plan must include services for which purchase will be self-directed by consumer.	
Plan must include services for which control will be self-directed by consumer.	
Plan must prevent provision of unnecessary services and supports.	Who decides whether or not the service and support is necessary? May want to specify: plan does not provide services and supports consumer deems unnecessary.

Person-Centered Service Plan (cont.)		
Plan must prevent provision of inappropriate services and supports.	Who decides whether or not the service and support is appropriate? May want to specify: plan does not provide services and supports consumer deems inappropriate.	
Plan must document that any modification of consumer's rights in provider-owned or controlled settings — including tenant protections; privacy; freedom and support to control schedules, activities, access to food, and visitors — must be supported by specific assessed need and justified in plan.	These consumer rights are discussed in this guide's Section III.	
<ul> <li>Specific and individualized assessed need.</li> <li>Positive interventions used prior to any modifications to plan.</li> <li>Supports used prior to any modifications to plan.</li> <li>Less intrusive methods to meet need that were tried but did not work.</li> <li>Clear description of condition that is directly proportionate to specific assessed need.</li> <li>Regular collection and review of data to measure ongoing effectiveness of modification.</li> <li>Time limits for periodic review to determine if modification is still necessary.</li> <li>Consumer's informed consent.</li> <li>Assurances the interventions and supports will cause no harm to consumer.</li> </ul>	In discussing potential modifications and considering less restrictive alternatives, consumers could benefit from assistance from protection and advocacy agencies, independent living centers, and/or long-term.	
Plan must be reviewed least every 12 months, when consumer's circumstances or needs have changed significantly, or on consumer's request.	State should specify how consumer requests reassessment.  To ensure adequate dialogue, consumer from the outset could be offered opportunity to set up more frequent meetings.	

#### **Table Endnotes**

- A. 79 Fed. Reg. at 3,005.
- B. CMS, Exploratory Questions to Assist States in Assessment of Residential Settings, at 1.



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