



Understanding and Advocating for Effective Implementation of the Home and Community-Based Services Settings Rule

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Advocating for Effective
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Home and Community -
Based Services Settings
Rule

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Understanding and Advocating for Effective Implementation of the HCBS Settings Rule

INTRODUCTION

An important part of the practice of many elder law attorneys is assisting clients to receive and then benefit from Medicaid home and community-based services (HCBS). In March 2014, the Centers for Medicare and Medicaid Services (CMS) published the first ever regulations establishing standards for the settings in which HCBS are provided.¹ These regulations will impact the services, quality of life, and rights of HCBS care recipients, as well as the environment in which they receive those services. Each state must develop and implement a plan for how it will come into compliance with the HCBS rules. The involvement of advocates, including elder law attorneys, in influencing the plan and monitoring its implementation is critical. This guide is designed to provide elder law attorneys with a better understanding of the HCBS settings rule and how they can advocate for a strong, effective system that achieves the spirit and intent of the rule.

OVERVIEW OF THE RULE

Purpose²

The purpose of HCBS Medicaid services is to be an alternative to institutional settings. However, over the years, HCBS funding has been used to pay for services and supports provided in settings that can feel institutional in nature, such as some assisted living facilities³

¹ 42 C.F.R. §§ 430-431, 435-436, 440-441, & 447

² 42 C.F.R. § 430 et al. See also Dep't of Health & Human Serv. Ctr. for Medicare & Medicaid Serv. *CMCS Fact Sheet: Home and Community Based Services*, Jan. 10, 2014 available at <https://www.medicaid.gov/medicaid/hcbs/downloads/final-rule-fact-sheet.pdf>

³For the purposes of this guide, the term “assisted living facility” will be used as an example of a residential setting. However, residential settings also include adult foster care homes, residential care homes, group homes, etc. The terms vary from state to state.

or group homes. Consequently, a primary reason for promulgating this rule is to define the qualities that make a setting a home that is truly part of a larger community.

A second reason for the rule is to ensure that people receiving HCBS are truly part of the community in which they live. There are currently settings where the only people a consumer would encounter in the course of the day are others with similar disability and staff – a consumer may rarely if ever get to leave the home and interact with others. These individuals are isolated from the community and denied the benefits of community living.

Finally, the rule is designed to improve the quality of people’s lives and provide them with increased choice and added protections.

What the rule applies to

The rule applies to all settings where HCBS are delivered under three Medicaid “authorities.” Settings include non-residential settings, such as adult day services centers, and residential settings, such as assisted living facilities. Authorities give the federal government authorization to restructure traditional Medicaid. The three authorities are:

- 1915 (c) Home and Community-Based Services (HCBS) waiver.⁴ This waiver has been in existence for years. It allows states to provide LTSS in community settings as an alternative to institutional settings.
- 1915 (i) HCBS state plan option.⁵ States can amend their Medicaid state plan to offer HCBS as a state plan optional benefit instead of as a waiver.
- 1915 (k) Community First Choice.⁶ This is a program created by the Affordable Care Act that allows state to provide home and community-based attendant services and supports for beneficiaries on a statewide basis.
- Section 1115 waiver. This waiver permits states to implement an experimental, pilot or demonstration project that is likely to promote the objectives of the Medicaid program.⁷

Definition of a home and community-based setting: Requirements

i. All settings

The rule sets forth the characteristics a setting must have in order to qualify as a home and community based setting. The HCBS setting requirements establish an outcome-oriented

⁴ 42 C.F.R. § 441

⁵ 42 C.F.R. § 441.710

⁶ 42 C.F.R. § 441.530

⁷ <https://www.medicaid.gov/medicaid/section-1115-demo/about-1115/index.html>

definition that focuses on the nature and quality of individuals' experiences rather than one based solely on a setting's location, geography, or physical characteristics.⁸ According to CMS, "These are the qualities most often articulated by persons with disabilities as key determinants of independence and community integration."⁹ They are:

a. Community integration

The setting:

- Is integrated in and supports access to the greater community
- Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and
- Ensures the individual receives services in the community to the same degree of access as individuals not receiving Medicaid HCBS

This language around community integration strengthens an individual's right to receive services in the most integrated setting possible. The rule promotes full participation in the community in terms of where people live, participate in activities and when applicable, work. It means that people of any age with disabilities have the right to be a part of the community to the same extent as people without disabilities.

b. Choice and control

The setting:

- Provides opportunities to control personal resources
A person's ability to access and spend their own funds empowers them and places them more in charge of their lives.
- 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

This provision underscores two critical points: first, that it is the consumer that is to choose the setting, and second, that the consumer is to have real choices, that is, options to live and receive services in places that are for people with and without disabilities.

⁸ Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule (CMS 2249-F/2296-F). January 10, 2014.

⁹ 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; Final Rule, 79 Fed. Reg. 2948, 2952 (Jan. 16, 2014) (codified 42 C.F.R. § 441).

- Optimizes individual initiative, autonomy, and independence in making life choices

Mandating that individuals in all HCBS settings are able to make choices about aspects of their lives that are important to them will give consumers much greater control and permit them to live more fulfilling and meaningful lives. These provisions help turn a “setting” into a home.

- Facilitates individual choice regarding services and supports and who provides them

The ability to make these decisions gives individuals more control over their lives, which can translate into improved psychosocial and even physical well-being. In addition, this provision allows consumers to choose to continue to receive services and supports from providers with whom they have developed a relationship. This promotes continuity and often improved quality.

However, choice of service provider is somewhat limited for people living in a provider-owned or controlled setting. CMS indicates that if the consumer makes an informed choice to reside in a setting that provides both housing and services, the consumer will be considered to have chosen that provider as the provider of services as well.

c. Rights

The setting:

- Ensures an individual’s rights of dignity, privacy, respect, and freedom from coercion and restraint

These requirements will help improve the quality of life for many individuals.

ii. Provider-owned or controlled residential settings¹⁰

CMS established a set of additional standards to ensure that individuals who are living in settings in which the individual does not have ownership or control, will be afforded the same opportunities and community access as individuals living in their own private or family homes. Provider-owned or controlled residential settings must meet the regulations that apply to all

¹⁰42 C.F.R. § 441.530. See also Dep't of Health & Human Serv. Ctr. for Medicare & Medicaid Serv. *CMCS Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule*, Jan. 10, 2014 available at <https://www.medicaid.gov/medicaid/hcbs/downloads/hcbs-setting-fact-sheet.pdf>

settings and must also comply with these extra provisions.¹¹ These standards and their importance are discussed below.

a. Enforceable agreement

Consumers must have a right to reside in a specific living unit within the facility. The right must be established by a legally enforceable agreement, such as a lease.

b. Reasonable protection from eviction

The HCBS recipient must have protections that are at least equivalent to those provided to rental tenants in the state. This means the right to notice of eviction and the right to respond to the landlord's desire to evict him or her. If the state's landlord/tenant law does not apply to the setting, the provider and HCBS recipient must enter into a written agreement that establishes comparable protections. This will be the first time in some states that assisted living facility residents have any eviction protections at all.

c. Privacy

Individuals can choose between single or private occupancy and shared occupancy, although this "choice" is limited by the person's ability to pay for a private room. CMS has indicated that this provision does not mean that individuals have the right to a private room or unit; it means that consumers must have the right to options of residential settings and the state must assure that some of those settings have private rooms available. This means that "privacy" may have to be provided within the context of a shared living arrangement.

d. Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors

One of the defining features of a person's home is that it can be locked, giving the person living in the home control over who is allowed to enter. Residents of many residential care facilities have previously not had such control. Because nursing homes do not have doors that lock, this feature distinguishes a home and community-based setting from an institutional one. CMS has indicated that this regulation does not require individuals to provide keys to anyone and that this language is intended to curtail the issuing of resident keys to all employees or staff regardless of the employee's responsibilities. If the resident chooses to give keys to certain staff, they should have a say and agree with who that employee or employees are.

¹¹ 42 C.F.R. § 441.530; See also Dep't of Health & Human Serv. Ctr. for Medicare & Medicaid Serv. *CMCS Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule*, Jan. 10, 2014, available at <https://www.medicaid.gov/medicaid/hcbs/downloads/hcbs-setting-fact-sheet.pdf>.

e. Choice of roommate

This choice gives residents a greater sense of control and autonomy and can contribute to better quality of life.

f. Control over their own schedules and activities

The freedom for individuals to decide how they spend their time is an essential element of non-institutional life. This control promotes a sense of independence and allows people to direct their own lives.

g. Right to furnish and decorate their units as permitted under lease/agreement

As with choice of roommate, this right gives residents a greater sense of control and autonomy. In addition, being allowed to decorate/furnish a unit with items residents cherish and have had for many years also makes the unit more homelike.

h. Right to visitors at any time

Not all assisted living facilities/residential care facilities currently allow people to visit residents at any time. Many have established visiting hours that limit visitation time. This right will enhance existing visitation rights for many and give others this right for the first time. Deciding when and if they want to see people gives residents more independence and control over their lives, helps improve quality of life and creates a greater sense of home. This right to visitation includes overnight visits, but CMS notes in the preamble¹² it would be reasonable for there to be limitations on the amount of time a visitor can stay in order to avoid occupancy issues. Such limitations should be clearly stated in a lease, residency agreement, or other form of written agreement.

i. Access to food at any time

Being in one's own home, means the ability to eat something at any time, not just at meal times. It also means that an individual does not have to tie their schedule to set meal times.

j. Physical accessibility of the setting

Currently there are some settings that are not physically accessible to consumers yet receive HCBS waiver funding. This provision ensures that all residents who choose this setting and whose services and supports will be paid through an HCBS waiver can access assisted living/residential care facilities.

¹² HCBS Final Rule, 79 Fed. Reg. 2948, 2966.

iii. Modifications¹³

The Medicaid HCBS rules allow the above requirements – with the exception of the provision about the accessibility of the setting – to be modified under certain circumstances for a particular consumer.

In general, the modification process is as follows:

The provider must:

- a. **Assess what the specific and individualized need is for the individual resident.**
Requiring that the modification be based on a specific assessed need better ensures that the modification is geared toward individual need and not just an overall general condition (e.g. “dementia”).¹⁴
- b. **Try other interventions and “positive” supports to address the need first before attempting more restrictive measures.**
These interventions must have failed before the proposed modification is applied. The measures that have been taken must be documented. Similar to the use of physical restraints in nursing homes, modifications cannot be implemented unless other approaches have been tried, documented and shown to have failed. A modification should be a last resort, and only used when absolutely necessary.
- c. **Limit the proposed modification to the minimum necessary to address the need and clearly describe it.**
This language helps safeguard against the use of unnecessarily restrictive methods for providing person-centered services and supports.¹⁵
- d. **Set a time limit for how long the modification will be tried.**
CMS does not indicate what the time limits should be, but it indicates that a modification should never become a “standing order” without time limitations.¹⁶ In addition, the preamble states that “reviews and any needed revision of the independent assessment and the person-centered service plan, must occur at least every 12 months, when the individual’s circumstances or needs change significantly, and at the request of the individual.”¹⁷

¹³ 42 C.F.R. § 441.710(a)(1)(vi)(F)

¹⁴ HCBS Final Rule, 79 Fed. Reg. 2948, 2978.

¹⁵ HCBS Final Rule, 79 Fed. Reg. 2948, 2990.

¹⁶ Dep't of Health & Human Serv. Ctr. for Medicare & Medicaid Serv. *Questions and Answers Regarding Home and Community-Based Settings*, at 13, available at <https://www.medicare.gov/medicaid/hcbs/downloads/q-and-a-hcb-settings.pdf>.

¹⁷ HCBS Final Rule, 79 Fed. Reg. 2948, 2979.

e. Obtain informed consent from the individual.

This provision is designed to make sure the individual agrees to the modification conditions.¹⁸

f. Provide assurance that the modification will not harm the individual.

CMS does not provide any guidance on how “harm” should be defined nor what should be considered in determining whether a modification will harm the individual.

g. Gather information to assess the effectiveness of the modification on a regular basis. Determine if it needs to continue or can be terminated.

In its Q&A, CMS states that it has not established a uniform federal standard for measuring the effectiveness of past interventions. The reason is because “Each individual is unique, so considerations for each individual’s person-centered plan will be different, including the appropriate use of interventions. The person-centered planning team must consider what is a reasonable amount of time (e.g., week, month) to evaluate the effectiveness of an intervention, based on the individual circumstances, as well as weigh the risk, success and amount of time given for a response.”¹⁹

PROCESS FOR STATES TO COMPLY WITH THE HCBS RULE

Statewide Transition Plans

Each state must develop a statewide transition plan (STP) that lays out how the state will come into compliance with the HCBS requirements.²⁰ An STP includes the state’s assessment of the extent to which its regulations, standards, policies, licensing requirements, and other provider requirements ensure settings that comport with the requirements and describes actions the state proposes to assure full and on-going compliance with the HCBS settings requirements, with specific timeframes for identified actions and deliverables. The rule requires that the State must consider and modify the transition plan, as the State deems appropriate, to account for public comment.

Below is a more detailed description of the elements the STP must contain:

¹⁸ HCBS Final Rule, 79 Fed. Reg. 2948, 2980.

¹⁹ Dep’t of Health & Human Serv. Ctr. for Medicare & Medicaid Serv. *Questions and Answers Regarding Home and Community-Based Settings*, at 13, available at <https://www.medicare.gov/medicaid/hcbs/downloads/q-and-a-hcb-settings.pdf>.

²⁰ 42 C.F.R. § 441.710(a)(3)

i. Assessment

- a. Systemic assessment:** A review and analysis of the degree to which statutes, licensing/certification regulations, guidelines, policy and procedure manuals, provider manuals and provider training pertaining to all setting types in which HCBS is provided comply with the HCBS requirements. States must determine if their regulations, policies, etc. comply, partially comply, conflict or are silent vis-à-vis the HCBS rule.
- b. Site-specific assessment:** An evaluation of all settings in which HCBS are provided and where HCBS participants reside to determine the settings that 1) fully comply with the Federal requirements; 2) do not meet the Federal requirements and will require modifications; 3) are presumptively non-home and community-based but for which the state will provide justification/evidence to show that those settings do not have the characteristics of an institution and do have the qualities of home and community-based settings (to be evaluated by CMS through the heightened scrutiny process); and 4) cannot meet the Federal requirements. The assessment should focus on the experience of the individual, not just on the physical characteristics or location of the setting.

States are conducting this assessment initially through provider self-assessments. States must then validate their initial assessment findings and can use a range of methods to do so (e.g. onsite visits, consumer feedback, review of data from entities such as case managers).

ii. Remediation

- a. Systemic remediation:** The actions the state will take to bring its standards into compliance with the HCBS requirements. This can include new requirements in statute, licensing standards or provider qualifications; revised service definitions and standards; revised provider contracts and/or manuals; and revised training requirement/programs/manuals.
- b. Site-specific remediation:** The actions the state will take to assure that all settings comply with the federal rule. Approaches might involve requiring corrective plans for specific providers, statewide training, and/or technical assistance. Providers can come into compliance in many ways, such as changing practices, policies, and procedures.

In certain cases, a provider may not be able to meet the HCBS requirements. This is most likely to happen in situations where the setting is considered isolating and the state cannot provide sufficient evidence to CMS that the setting has HCBS qualities (see

section about heightened scrutiny below). When this situation arises, states will need to remove the provider from the HCBS program and relocate beneficiaries. However, Statewide Transition Plans indicate a willingness to go to great lengths to help providers comply with the rule. In addition, if a setting does not meet HCBS standards, Medicaid payments might be available under other state plan authorities.²¹

The state must provide timelines for its actions in both systemic and site-specific remediation. Although CMS has not issued any guidance about what those timelines should be, remediation must be complete by March 17, 2022 when all states must be in full compliance with the HCBS settings criteria.

iii. Monitoring

The state must outline how it will 1) monitor its remedial actions to come into compliance by 2022, and 2) establish ongoing monitoring and quality assurance processes that will ensure all settings providing HCBS continue to remain fully compliant with the rule.

iv. Relocation of HCBS beneficiaries

When relocation of beneficiaries is part of the state's remedial strategy, the STP must develop a relocation process that includes:

- Reasonable notice to beneficiaries and due process to these individuals
- Timelines
- The number of beneficiaries impacted
- A person-centered planning process that 1) provides each affected beneficiary with the opportunity, the information, and the supports to make an informed choice of an alternate setting that complies with the HCBS regulations, and 2) ensures that services/supports are in place before the individual transitions

v. Public input

The STP must describe its process for obtaining, reviewing, and responding to public input. All states provided a 30-day public notice and comment period when they first submitted their STP to CMS. States must also seek public comment when there are "substantive" changes in a STP

²¹ Dep't of Health & Human Serv. Ctr. for Medicare & Medicaid Serv. *Questions and Answers Regarding Home and Community-Based Settings*, at 6, available at <https://www.medicaid.gov/medicaid/hcbs/downloads/q-and-a-hcb-settings.pdf>.

(for example, when additional assessment of a setting has resulted in a change in findings or where the state adds more specific remedial action and milestones). Public input must be considered, and the state must modify the STP as it feels is appropriate to account for public comment. The STP must include a summary of the comments received during the public notice period, any modifications to the transition plan based upon those comments, and reasons why other comments were not adopted.

States are encouraged to seek input from a wide range of stakeholders representing consumers, providers, advocates, families, and other related stakeholders. CMS states that the process for individuals to submit public comment should be convenient and accessible for all stakeholders, particularly individuals receiving services. CMS requires states to post the Statewide Transition Plans on their website in an easily accessible manner and include a website address for comments. At least one additional option for public input, such as public forums, is required.

CMS indicates that it would be useful for the states to use public input in the assessment of the state's progress on the milestones approved in the Statewide Transition Plan (see next section).²²

Milestones

The major milestones in coming into compliance with the HCBS rule and where states are with this process as of October 1, 2017 are as follows:

- Submission of the proposed statewide transition plan to CMS.
 - Status: All states have submitted their proposed plans
- Notification by CMS to the state of “Clarifications and/or Modifications required for Initial Approval” - referred to as CMIA. Receiving the CMIA letter means that the state has met the public comment, input, and summary requirements. The letter identifies issues that must be resolved in order for the STP to receive initial approval.
 - Status: All states have received CMIA notification.
- CMS Initial Approval with Milestones and a Resubmission Date. Approval means that issues have been addressed sufficiently to continue moving forward. CMS now requests clarification in areas of concern and identifies what the state still must do before final approval will be granted. States with initial approval have conducted their

²² Dep't of Health & Human Serv. Ctr. for Medicare & Medicaid Serv. *Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Setting Requirements*, Sept. 5, 2014, at 6-7, available at <https://www.medicare.gov/medicaid/ltss/downloads/statewide-transition-plan-toolkit.pdf>.

systemic assessment and indicated what remediation steps they will take and are in the midst of their site-specific assessment.

- Status: 37
- Final Approval from CMS. This stage signifies that public comment, input, and summary requirements are met, the STP has provided all necessary information including but not limited to: systemic assessment, site-specific assessment, settings presumed to have institutional characteristics, information regarding heightened scrutiny or the state’s decision to let the presumption stand, and clear remedial steps with milestones are delineated.
 - Status: 4
- Approved Plan: The CMS approved STP.
 - Status: 1

The CMS website chart²³ shown below indicates the status for each state and is updated as states meet these milestones.

The screenshot shows the Medicaid.gov website with the following table of Statewide Transition Plans:

| State | Proposed Plan URL ¹ | CMA ² | Initial Approval ³ | Final Approval ⁴ | Approved Plan ⁵ |
|-------------|--------------------------------|---------------------------|-------------------------------|-----------------------------|----------------------------|
| Alabama | Available ⁶ | Available (PDF 124.53 KB) | Available (PDF 177.71 KB) | | |
| Alaska | Available ⁶ | Available (PDF 81.32 KB) | Available (PDF 97.76 KB) | | |
| Arizona | Available ⁶ | Available (PDF 81.34 KB) | Available (PDF 95.37 KB) | | |
| Arkansas | Available ⁶ | Available (PDF 141.83 KB) | Available (PDF 169.66 KB) | Available (PDF 150.61 KB) | |
| California | Available ⁶ | Available (PDF 117.53 KB) | | | |
| Colorado | Available ⁶ | Available (PDF 137.89 KB) | | | |
| Connecticut | Available ⁶ | Available (PDF 85.91 KB) | Available (PDF 167.18 KB) | | |
| Delaware | Available ⁶ | Available (PDF 116.09 KB) | Available (PDF 137.59 KB) | | |

²³ <https://www.medicaid.gov/medicaid/hcbs/transition-plan/index.html>, October 10, 2017

OPPORTUNITIES FOR ADVOCACY TO PROMOTE YOUR CLIENTS' BEST INTERESTS

This section focuses on suggestions for how elder law attorneys can advocate for effective implementation of the HCBS rule.

Getting involved

There are several different ways to engage in advocacy related to the rule.

i. **Participate in a state task force or advisory group.**

Some states have created a task force or advisory group made up of external stakeholders to assist with implementation of the rule.

Example:

In Minnesota, the Department of Human Services (DHS) formed an HCBS rule advisory group that represents experts from county government, service providers, managed care organizations and advocates.²⁴ The group has:

- Developed recommendations on policy expectations and practice considerations for DHS.
- Reviewed the HCBS rule standards and discussed expectations and responsibilities of case managers, care coordinators and providers, as well as the licensing authority responsible to enforce the service standard.
- Supported DHS in identifying characteristics of settings that may have the effect of isolating.
- Developed standards that will inform system changes and how settings will be assessed via the provider attestation.

Moving forward, the state will engage the advisory group regularly throughout the remainder of the transition period to provide input as we make the transition plan part of our operations.

²⁴ Minn. Dep't of Human Serv. *Minnesota's Home and Community-Based Services Final Rule Statewide Transition Plan*, Dec. 2, 2016, at 10, available at https://mn.gov/dhs/assets/12022016-HCBS-statewide-transition-plan_tcm1053-284362.pdf.

Elder law attorneys interested in ongoing advocacy throughout the implementation process should consider participating in such an advisory group. These groups provide participants with an opportunity to share their expertise and give input to the state on various components of the plan and its implementation. Contact the state Medicaid office to learn if and how individuals can join.

ii. Work with other elder law attorneys in the state.

One way to find attorneys interested in HCBS rule advocacy is to contact the state chapter of the National Academy of Elder Law Attorneys. A second way is to connect with attorneys in the elder law and disability section of the state bar in states that have such a section.

iii. Join with other advocates in the aging and disability community and work together.

Aging groups might include the State Long-Term Care Ombudsman Program, Area Agencies on Aging, the Alzheimer's Association, and the state AARP chapter; disability organizations to connect with include the Disability Rights Network state agency, the state chapter of The ARC and programs that are part of the Association of University Centers on Disabilities network.

iv. Advocate as an individual.

States must permit the public to provide input on implementation of the HCBS settings rule. Some ways to do this are to:

- Comment on the Statewide Transition Plan (STP). The process for submitting public comment must be convenient and accessible. The Statewide Transition Plan must be posted on the State's website and include a website address for comments. In addition, the State must have at least one additional option for public input, such as a public forum. The Statewide Transition Plan must include a description of the public input process.
- Email input to the state at any time. Most states have a dedicated email box and/or website to accept feedback.
- Share recommendations/comments with the Center for Medicaid and Medicare Services at hcbs@cms.hhs.gov.

While the focus of this guide is on working toward effective implementation of the HCBS rule, elder law attorneys should also consider advocating at both the state and local levels for non-Medicaid funding for services at home and in the community. Multiple funding streams strengthen the setting's ability to provide quality services that benefit beneficiaries.

Where to start

Regardless of which advocacy approach is chosen, the best first step is to review the state's transition plan. Statewide transition plans (STP) can be found on this CMS webpage:

<https://www.medicaid.gov/medicaid/hcbs/transition-plan/index.html>

Tip: This CMS webpage does not always present the most recent Statewide Transition Plan. To learn what the most recent public plan is, try going to www.hcbsadvocacy.org and clicking on State Resources. Alternatively, review the Initial Approval letter, found on the CMS webpage listed above and then try to obtain it either by asking the state or conducting an online Google search.

The STP contains timelines for both standards (rules, statutes, provider manuals, etc.) and settings to come into compliance. Examining the transition plan will permit elder law attorneys to determine where their state is in its plan and consequently what advocacy action might be most appropriate.

Advocacy and the STP

While there are advocacy opportunities at every stage of the transition plan, this guide will focus on advocacy strategies related to assessment, remediation, and relocation of beneficiaries.

i. **Assessment**

a. **Systemic assessment advocacy**

- Review the state's assessment of the extent to which its laws, rules, regulations, policies, or other requirements comply with the HCBS settings rule. Each state must provide a written description of its current compliance.

Most states have provided that information in the form of a "crosswalk." The crosswalk is the comparison between each provision of the HCBS rule and the corresponding state regulation (or the regulation that is the closest to the HCBS provision). It is found in the statewide transition plan. Below is an example²⁵ of what a crosswalk looks like:

²⁵ Ohio's HCBS Transition Plan, March 6, 2017, Revised Initial Approval, p.127, <http://www.medicaid.ohio.gov/Portals/0/For%20Ohioans/Programs/HCBS/Transition/HCBS-StatewideTransitionPlan.pdf?ver=2017-03-28-151841-133>

**Appendix 3: NF-LOC Waivers
System Remediation Grid
Initial Approval: June 2, 2016**

The system grid describes the impact of the federal regulation on applicable State statutes, administrative rules, administrative and operational policies.
*The proposed timelines are contingent upon approval of the plan by the Centers for Medicare and Medicaid (CMS)

| Regulation | Areas of Compliance | Remediation Required | Action Steps | Timeline* |
|--|---|--|---|---|
| Setting is integrated in and supports full access of individual receiving Medicaid HCBS to the greater community, includes opportunities to seek employment and work in competitive integrated settings, opportunities to engage in community life, and to control personal resources to the same degree of access as individuals not receiving Medicaid HCBS. | The State regulation, policy or other standards are partially compliant. The state's determination was the result of the assessment methodology outlined on pages 17-20. Assisted Living Service Residents Rights ORC 3721.13 Licensure Rules OAC 3701-17-50 Adult Day Health Service | Adopt and implement an overarching HCBS Waiver Administration rule that details the CMS HCBS settings characteristics required for all provider controlled settings. Amend the following administrative rules to incorporate HCBS community integration/access characteristics. OAC 5160-44-01 (B) (1) requires the setting to be fully integrated. http://www.registerofohio.state.oh.us/pdfs/5160/0/44/5160-44-01_PH_OF_N_RU_20160415_135_2.pdf | Rule Process: Utilize rule development and filing processes which includes individuals, advocates, and providers. Training: Modify Provider and case management operational manuals and applicable forms as needed. Issue guidance to impacted providers and case management entities. Ongoing Compliance: On site I provider reviews, including the experience of individuals residing in the setting, conducted for each | July 1, 2015-July 1, 2016 January 1, 2016-June 30, 2016 July 1, 2017-March 17, 2019 |

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- Check the state's systemic assessment for accuracy. In some states, CMS only completed a spot check of 50% of the state's assessment, so it is possible that the state has erroneously concluded that a state regulation complies with the HCBS settings rule. The state's initial approval letter found on the CMS Statewide Transition Plans chart (<https://www.medicaid.gov/medicaid/hcbs/transition-plan/index.html>) indicates if a spot check only was conducted.
- Compare the federal regulation to the rules, policy manuals, etc. the state has identified. Look carefully at state determinations that the rule/manual is compliant. If it appears that the state standard is not in line with the federal regulation and/or that the proposed revision is not adequate, communicate the findings with the state and with CMS.

To share findings with the state, contact the state Medicaid agency and ask who is the lead person for the STP. The Medicaid Directors Association website provides a clickable map that connects to the state's Medicaid agency. <http://medicaiddirectors.org/about/medicaid-directors/>

To share findings with CMS, email: hcbs@cms.hhs.gov

- Identify concerns raised by CMS in its initial approval letter to the state and review the revised STP to make sure the state is responsive to those issues. If

the state is not adequately addressing the issues, inform the lead person at the Medicaid state agency and CMS as indicated above.

b. Site-specific assessment advocacy

- Become familiar with the characteristics of both non-residential and residential settings that meet the HCBS requirements. CMS has issued “exploratory questions” for both settings.

Non-residential:

<https://www.medicaid.gov/medicaid/hcbs/downloads/exploratory-questions-non-residential.pdf>

Residential: <https://www.medicaid.gov/medicaid/hcbs/downloads/exploratory-questions-re-settings-characteristics.pdf>

- Advocate for the assessment process to be as thorough as possible. Once the provider self-assessments have been completed, push for a robust validation process that includes:
 - As many state onsite evaluations as possible to validate the provider self-assessment. It is very difficult to accurately assess a setting from an office that is miles away.

Example: Mississippi will validate provider self-assessments for all HCBS setting sites for a total of 423 sites.

To access: Mississippi Division of Medicaid Revised Statewide Transition Plan Summary 1915(c) and 1915(i) Home and Community-Based (HCB) Programs Compliance with HCB Settings November 28, 2016

<https://medicaid.ms.gov/wp-content/uploads/2016/11/MS-Statewide-Transition-Plan-Summary-and-Timeline-11.28.2016.pdf>

p. 152

- Consumer feedback that is obtained using a participant survey/assessment that is comprehensive and high quality. Look in the STP to find the participant/survey used by the state.

Example: Indiana contracted with The Indiana Institute on Disability and Community (IIDC) to design and develop an “individual experience survey” (IES) to be completed by participants when able or the person who knows them best. The survey was designed to identify and analyze the experiences and choices that individuals with intellectual and developmental disabilities have in their daily lives. Responses garnered

from the IES will be used to validate the responses from the provider self-assessment to gain a global prospective of compliance.

The IES is available at: http://www.in.gov/fssa/files/IES_Report_2016.pdf

To access: Statewide Transition Plan for Compliance with Home and Community-Based Services Final Rule State of Indiana March 2017 Version 6 <http://www.in.gov/fssa/files/IN%20FSSA%20HCBS%20STP%20-%20V6%202017.03.30.pdf> ; pp. 84-85

- Share the participant assessment/survey with clients and help them understand it and prepare to respond in a meaningful way if interviewed.
- Advocate for the state to publicly share its initial setting assessment results (list of settings that meet or do not meet HCBS requirements). Elder law attorneys should review the list to see if, based on their knowledge, there are settings that have not been appropriately identified. Consider asking clients in any of the settings for their input. Then, make a case for how the characteristics of the setting do or do not match the HCBS settings rule criteria. Share findings/information with the state.

ii. Remediation

a. Systemic remediation advocacy

- Review the revisions to any licensure or waiver regulations the state is proposing in its Statewide Transition Plan to make sure they comply with the HCBS requirements. Report to the state any proposed regulations that do not comply.

Example: New Hampshire: To comply with the HCBS regulation about access to food at any time, the crosswalk in the New Hampshire STP indicated that their rules for adult family care residences would be revised so that a waiver recipient could:

... have a meal at any time and place different from when scheduled meals are provided, including the option to eat privately or in a seat that is not assigned; and request an alternative meal from the meal that is served during scheduled meals.

However, this does not remedy the noncompliance because it only addresses meals and does not require the setting to provide access to food at any time.

To access: New Hampshire Statewide Transition Plan Appendix
<https://www.dhhs.nh.gov/section-1115-waiver/documents/nh-stp-attach-05262016.pdf>; p. 63

- Advocate for regulations for assisted living and adult day services centers to be revised. This can be accomplished using four different approaches:
 1. Revise state licensure regulations to comply with the HCBS settings rule. This is the “gold standard” for advocacy for three important reasons:
 - By changing licensure requirements, individuals in all facilities or centers benefit, not just HCBS recipients in facilities/centers that receive Medicaid funding.
 - Revising regulations is more permanent than simply revising a provider manual or contract.
 - Because licensing rules are tied to a system of inspection, enforcement, and complaint investigation, there is a better chance that providers will comply and there is some recourse for consumers who have concerns about care and/or services.

Example: North Dakota revised its licensure regulations for adult foster care in order to come into compliance with the HCBS rule. Its STP indicated that “*Requirements will be added to ND Admin Code 75-03-21 Licensing of Foster Homes for Adults*”

To access: <http://www.legis.nd.gov/information/acdata/pdf/75-03-21.pdf>, p. 13

Example: Oregon revised its licensure rules for residential care and assisted living facilities to incorporate all HCBS settings requirements.²⁶

Residential care and assisted living facilities are also required to adhere to Home and Community-Based Services, OAR 411-004. For purposes of these rules, all residential care and assisted living facilities are considered home and community-based care settings and therefore shall be referred to as "facility."

To access: http://www.dhs.state.or.us/policy/spd/rules/411_054.pdf, p. 1

2. Revise state waiver regulations. Many states are revising the waiver regulations that apply to assisted living and adult day centers to bring them into compliance. While these rules would benefit only HCBS participants in these settings, rule changes are more lasting than merely revising policy procedures or contracts. In many cases, states are adopting the HCBS requirements verbatim for each setting.

²⁶ Or. Admin. R. 411-54-0000 (Aug. 1, 2017).

A number of states have chosen to promulgate an “overarching administrative rule” that applies the federal HCBS settings rule across all of their waiver programs.

Example: Ohio promulgated an overarching administrative rule addressing HCBS characteristics across the waiver programs in order to better ensure clarity and consistency across settings.

To access: <http://codes.ohio.gov/oac/5160-44-01v1>

3. Strengthen and expand state licensure and/or waiver regulations. The HCBS settings rule language is broad, general, and vague. Adding more detailed and comprehensive provisions better protects consumers. As noted above, it is preferable to advocate for stronger state licensure rules since those benefit all residents/participants, not just HCBS recipients. CMS is quite clear that states may set standards higher than the minimums set forth in the rule.
4. Advocate for tiered standards. In this approach, existing providers must meet the minimum standards established by CMS for HCBS settings, but the state may require future providers to comply with higher, more stringent standards.

Example: Minnesota will require higher standards for designated new service settings. It plans to apply a higher state standard to new developments/settings serving people with disabilities on certain specific waivers.

To access: https://mn.gov/dhs/assets/12022016-HCBS-statewide-transition-plan_tcm1053-284362.pdf p. 27

Example: Indiana. For tier 2, Division of Aging (DA) will design, submit to CMS, and upon approval, implement a new Medicaid HCBS program. This program will include a congregate, residential option for consumers.... Standards will be developed to support a new certification system.... These standards will be based on HCBS characteristics, Money Follows the Person qualified community setting guidelines, and state statute regarding housing with services establishments. Administrative rules will be amended to reflect these standards.

To access: Statewide Transition Plan for Compliance with Home and Community-Based Services Final Rule State of Indiana March 2017 Version 6 <http://www.in.gov/fssa/files/IN%20FSSA%20HCBS%20STP%20-%20V6%202017.03.30.pdf> pp. 46-47

- Argue that HCBS requirements that apply to a licensed certified provider must apply to all residents, not just HCBS recipients. In *Just Like Home: An Advocate's Guide to Consumer Rights in Medicaid*,²⁷ Justice in Aging makes the following case for this argument:
 - The relevant regulatory language in most instances refers to the rights of an “individual” without regard to whether or not the individual’s services are reimbursed through Medicaid. In a few instances, the regulatory language refers specifically to an “HCBS participant” or to “individuals receiving Medicaid HCBS,” indicating that the term “individual” by itself should not be limited to persons receiving Medicaid-reimbursed services.
 - It would make little sense for a facility to provide and honor the specified rights for Medicaid-eligible consumers, while denying those same rights to other consumers living in the facility. An intent of the regulations is to foster a non-institutional environment, and creating and maintaining such an environment requires fair treatment of all consumers, regardless of the consumer’s reimbursement source.

- Review any proposed regulations (licensure and/or waiver regulations) when they are out for public comment. Testify at the public hearing and/or submit written testimony.

- Get input from clients and their family members about the proposed regulations. Assist them in providing testimony/comments if they wish.

- Participate in the revision of contracts, manuals, etc.

- Advocate for more direction to be provided regarding modifications. This could take the form of regulations, sub-regulatory guidance, or instructions in provider

²⁷ Carlson, Eric et al., Justice in Aging, *Just Like Home: An Advocate's Guide to Consumer Rights in Medicaid HCBS*, May 2014, at 4, available at http://www.justiceinaging.org/wp-content/uploads/2015/03/RE_Advocates-Guide-HCBS-Just-Like-Home-05-06-14-2.pdf.

manuals. Areas where more detail would be helpful include time limits on modifications and determining the effectiveness of interventions.

b. Site-specific remediation advocacy

- Ask the state to provide examples of what remediation by a provider might look like or sample remediation plans. This would help other providers in coming into compliance.

Example: Nevada provides sample remediation plans.

To access:

[http://dhcfp.nv.gov/uploadedFiles/dhcfpnavgov/content/Home/WhatsNew/Remediation Plan Example.pdf](http://dhcfp.nv.gov/uploadedFiles/dhcfpnavgov/content/Home/WhatsNew/Remediation%20Plan%20Example.pdf)

- The primary way to engage in site-specific remediation is to be involved in the **heightened scrutiny**²⁸ process.

Under the HCBS settings rule, certain settings must be presumed to be institutional. These settings include any setting that:

- Is located in a building that is also a publicly or privately-operated facility that provides inpatient institutional treatment,
- Is located in a building on the grounds of, or immediately adjacent to, a public institution,
- has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS

A setting that meets one or more of these criteria is not automatically excluded from being considered HCBS. States can go through a process called “heightened scrutiny” in which they submit evidence to CMS supporting a claim that such a setting does not have the qualities of an institution and has the qualities of HCBS. CMS makes the final decision.

For more information, refer to CMS guidance on heightened scrutiny:

<https://www.medicaid.gov/medicaid/hcbs/downloads/home-and-community-based-setting-requirements.pdf>

²⁸ 42 C.F.R. § 441.301(c)(5)(v)

Elder law attorneys can pursue one or more of the following advocacy approaches:

- Advocate for the state to conduct site visits to all settings going through the heightened scrutiny process and to develop a site-visit tool to gather information/evidence about the setting. This creates a clear expectation and promotes consistency.

Example: Minnesota is developing a site-visit protocol to gather provider-specific evidence to overcome institutional presumption and seek input on the design from stakeholders

To access: Minnesota's Home and Community-Based Services Final Rule Statewide Transition Plan submitted to CMS Dec. 2, 2016

https://mn.gov/dhs/assets/12022016-HCBS-statewide-transition-plan_tcm1053-284362.pdf p. 47

Example: Indiana is developing a comprehensive tool to be used for on-site visits to ensure consistency upon all determinations. Trainings will be conducted with the state or contracted staff completing the site visit

To access: <http://www.in.gov/fssa/files/IN%20FSSA%20HCBS%20STP%20-%20V6%202017.03.30.pdf> p.95

- Push the state to closely examine a provider's assertions of community integration. HCBS beneficiaries should be able to participate in the community by themselves or with others. For instance, even if a provider's activity schedule indicates outings, is the state determining whether individuals are asked if they would like to go into the community by themselves, and if so, assisted to do so with staff support as part of a non-group activity?
- Recommend that the state inform HCBS recipients and family members about the heightened scrutiny process, whether their setting must go through the process, and if so, how to submit evidence regarding their own setting. Individuals receiving HCBS have first-hand knowledge of what the setting is like and have a lot at stake if their setting goes through the heightened scrutiny process.

Example: Indiana's STP indicates trainings will be conducted with providers and families to explain the heightened scrutiny process.

To access:

<http://www.in.gov/fssa/files/IN%20FSSA%20HCBS%20STP%20-%20V6%202017.03.30.pdf>, p. 95

Example: New Hampshire will notify the individual/family/guardian about the need for heightened scrutiny for a particular setting. The individual/family/guardian will also be notified of the results.

To access: New Hampshire Department of Health & Human Services Statewide Transition Plan, May 30, 2016 Amended June 28, 2016. pp. 133, 135
<https://www.dhhs.nh.gov/ombp/medicaid/documents/nh-stp-062816.pdf>

Example: Indiana will notify individuals prior to the site visit.

To access: <http://www.in.gov/fssa/files/IN%20FSSA%20HCBS%20STP%20-%20V6%202017.03.30.pdf> p.95

- Advocate for the state to publish all supporting evidence along with the names of each of the settings undergoing heightened scrutiny when it seeks public comment. Consumers and other interested parties need to be able to evaluate the information themselves and not rely on a summary.
- Advocate for the state to request information from the public about settings they believe are institutional but have not been identified by the state.

Example: Oregon indicated in its STP (August 2017) that it would develop an “HCBS Heightened Scrutiny Identification Worksheet” (HSIW) for residents, stakeholders, and the general public to “red flag” a setting that the state has not identified, but may require heightened scrutiny.

To access: <http://www.oregon.gov/DHS/SENIORS-DISABILITIES/HCBS/Documents/Oregon%20Amended%20HCBS%20STP%20FINAL%2008-01-17.pdf> p. 209

- Notify and provide information to the state about any client’s setting that appears to have institutional qualities but has not been determined to require heightened scrutiny.
- Review and evaluate evidence for any settings submitted for heightened scrutiny review in which clients receive services. Determine if the evidence is in line with client information/experience and whether the evidence shows that the setting has the necessary home and community-based characteristics. Remember that the physical location and characteristics of a setting do not necessarily mean that it does

not provide access to the benefits of community living. Submit written comments to the state indicating why or why not the setting should be considered HCBS and not institutional.

In their practice elder law attorneys are likely to have at least some clients who are couples living in a setting where different levels of care are provided on the same campus. This could be a community living option that is a combination independent living, assisted living and nursing home, such as a continuing care retirement community. Couples generally choose this setting so that they can be close to each other even if they have disparate needs.

CMS has indicated that “most Continuing Care Retirement Communities (CCRCs), which are designed to allow aging couples with different levels of need to remain together or close by, do not raise the same concerns around isolation ..., particularly since CCRCs typically include residents who live independently in addition to those who receive HCBS.”²⁹ However the state must review each multi-level community and make its own determination. If a couple’s community is subject to heightened scrutiny, elder law attorneys may want to submit as strong a case as possible for why their clients’ setting is not isolative.

- Share comments directly with CMS (email hcbs@cms.hhs.gov). Because the state only has to submit a summary of the public comments and responses, information about individual settings provided by advocates may not get to CMS by way of the state submission process.

iii. Relocation of HCBS participants

Research and experience have shown that relocating frail individuals, particularly when the move is not one they have chosen, can result in devastating physical and psychological harm,³⁰ often referred to as “transfer trauma.” The response to the stress caused by a transfer or relocation may include depression, manifesting as agitation; increase in withdrawn behavior; self-care deficits; falls; and weight loss.³¹ However, trauma and distress can be minimized when factors such as control, choice, decision-making, and sufficient time are part of the relocation process.

The STP must include the state’s process for relocating HCBS beneficiaries when a provider cannot or chooses not to comply with the HCBS settings criteria. As described above in the

²⁹ Guidance on Settings That Have The Effect Of Isolating Individuals Receiving HCBS From the Broader Community. CMS. <https://www.medicaid.gov/medicaid/hcbs/downloads/settings-that-isolate.pdf>

³⁰ Jackson, Kate, *Prevent Elder Transfer Trauma: Tips to Ease Relocation Stress*, Social Work Today, Jan. & Feb. 2015, at 10, available at <http://www.socialworktoday.com/archive/011915p10.shtml>.

³¹ Murtiashaw, Sherer, *The Role of Long-Term Care Ombudsmen in Nursing Home Closures and Natural Disasters*, National Long Term Care Ombudsman Resource Center, Jan. 2000, available at <http://ltcombudsman.org/uploads/files/issues/NORC-Ombudsmen-in-NH-Closures.pdf>.

section, “Process for States to Comply with the HCBS Rule,” CMS requires states to include certain minimal components in this process. However, given how challenging a change can be, particularly if it involves a physical move, elder law attorneys should advocate for the state to develop a robust, comprehensive process that includes as many of the elements below as possible. The majority of these recommendations are best practices drawn from various STPs.

Prior to relocation

- Develop a person-centered, informed choice relocation process that sets forth essential elements of person-centered practice and detailed step-by-step information to follow when a person moves from one setting to another. (Minnesota)

To access: <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-3825-ENG>

- Create an information sheet to educate participants about why relocation may be necessary, options, rights, and what to expect during the relocation process. (New Hampshire)

To access: <https://www.dhhs.nh.gov/ombp/medicaid/documents/nh-stp-062816.pdf> p. 137

- Create a support team to assist the individual. In addition to the individual, consider including the case manager; current residential staff; advocates such as the long-term care ombudsman; and others at the request of the individual. (Montana)

To access: State of Montana Home and Community Based Services Transition Plan, 12/21/16

<http://dphhs.mt.gov/Portals/85/hcbs/MasterDraftTransitioPlanClean.pdf>

See Section 3 – Member Transition Plan p.6

- Appoint one person to take the lead and play a key role to assure the person-centered planning process is utilized (Iowa). Team members provide the lead person with information and resources about services and supports that may be beneficial to the individual on a case-by-case basis. (Iowa)

To access: Iowa Home and Community-Based Services Settings Statewide Transition Plan

https://dhs.iowa.gov/sites/default/files/Approved_Initial_STP_Submitted.pdf p 76

- Track transition of individuals moved on a daily basis to ensure continuity of care. (Iowa)

To access: Iowa Home and Community-Based Services Settings Statewide Transition Plan

https://dhs.iowa.gov/sites/default/files/Approved_Initial_STP_Submitted.pdf
p.76

- Hold team conference calls to monitor transition progress at least weekly, with additional calls as needed. (Iowa)

To access: Iowa Home and Community-Based Services Settings Statewide Transition Plan

https://dhs.iowa.gov/sites/default/files/Approved_Initial_STP_Submitted.pdf
p.76

- Notify the individual and the provider who will no longer be eligible to deliver HCBS of the need to relocate simultaneously to ensure both parties are made aware at the same time. (Delaware)

To access: State of Delaware Statewide Transition Plan for Compliance with Home and Community-Based Setting Rule Updated March 30, 2016

<http://dhss.delaware.gov/dhss/dmma/files/statewidetransitionplan.pdf> p. 74

- Offer the individual the opportunity to visit other settings and assist him/her in visiting if he or she wishes (Montana)

To access:

<http://dphhs.mt.gov/Portals/85/hcbs/MasterDraftTransitioPlanClean.pdf> p.6

- Ensure that all services are in place in advance of the individual's relocation (Delaware)

To access: State of Delaware Statewide Transition Plan for Compliance with Home and Community-Based Setting Rule Updated March 30, 2016

<http://dhss.delaware.gov/dhss/dmma/files/statewidetransitionplan.pdf> p. 74

- Conduct an onsite review of the HCBS beneficiary's new setting prior to the beneficiary's relocation. (Delaware)

To access: State of Delaware Statewide Transition Plan for Compliance with Home and Community-Based Setting Rule Updated March 30, 2016
<http://dhss.delaware.gov/dhss/dmma/files/statewidetransitionplan.pdf> p. 74

- Allow an extension of time if necessary to find alternative HCBS compliant care or housing. Offer extensions on a case-by-case basis in order to meet the participant's needs. (Idaho)

To access: Idaho State Transition Plan
<http://healthandwelfare.idaho.gov/Portals/0/Medical/MedicaidCHIP/HCBS/TransitionPlanV4.pdf> p. 44

- Allow persons/beneficiaries one year's time to make an informed choice of alternate HCBS settings (Mississippi). According to CMS, states have until March 2022 to bring their HCBS programs into compliance with the rule. States can claim for federal matching funds for these services during the transition period.³²

To access: Mississippi Division of Medicaid Revised Statewide Transition Plan Summary 1915(c) and 1915(i) Home and Community-Based (HCB) Programs Compliance with HCB Settings April 24, 2015 <https://www.medicaid.ms.gov/wp-content/uploads/2015/04/MS-Statewide-Transition-Plan-Summary-and-Timeline-Clean.pdf> p. 7

After Relocation

- Coordinate with new setting staff to meet the needs for each individual being transitioned to a new setting. (Montana)

To access: State of Montana Home and Community Based Services Transition Plan <http://dphhs.mt.gov/Portals/85/hcbs/MasterDraftTransitioPlanClean.pdf> p. 6

- Monitor the transition to ensure successful placement and continuity of services. This entails touching base with members within the first month following transition, three months after transition and ongoing as part of regularly scheduled visits to monitor the success of the transition. (Delaware)

³² Dep't of Health & Human Serv. Ctr. for Medicare & Medicaid Serv. *Questions and Answers Regarding Home and Community-Based Settings*, at 12, available at <https://www.medicaid.gov/medicaid/hcbs/downloads/q-and-a-hcb-settings.pdf>.

To access: State of Delaware Statewide Transition Plan for Compliance with Home and Community-Based Setting Rule Updated March 30, 2016
<http://dhss.delaware.gov/dhss/dmma/files/statewidetransitionplan.pdf> p.4

Additional recommendations for creating a successful relocation process can be found in the report, *Successful Transitions: Reducing the Negative Impact of Nursing Home Closures*.³³

SPECIAL ISSUES

Dementia care

In order to comply with the HCBS requirements, all individuals - including people with dementia who may wander or exhibit “exit-seeking behavior” - must be free from coercion and restraint, and have access to the greater community. Concerns have been raised about how to meet these regulations in a way that keeps people with dementia safe in adult day centers and assisted living facilities.

i. Unsafe wandering and exit-seeking behavior

In particular, the question of whether “secure” units will be permissible has arisen. According to guidance from CMS³⁴, provider-controlled settings with Memory Care Units with “controlled-egress” can comply with the HCBS settings rule, but only if:

“... controlled-egress is addressed as a modification of the rules defining home and community-based settings, with the state ensuring that the provider complies with the requirements of 42 C.F.R. 441.301(c)(4)(F), 441.530(a)(vi)(F) and 441.710(a)(vi)(F). (Note: These are the requirements regarding modifications for the 1915(c) HCBS waivers; 1915(i) HCBS state plan options; and 1915(k) Community First Choice)

³³ Rudder, Cynthia, *Successful Transitions: Reducing the Negative Impact of Nursing Home Closures*, National Consumer Voice for Quality Long-Term Care, 2016, available at http://theconsumervoice.org/uploads/files/issues/CV_Closure_Report_-_FINAL_FINAL_FULL_APPENDIX.PDF.

³⁴ Dep't of Health & Human Serv. Ctr. for Medicare & Medicaid Serv., *FAQs concerning Medicaid Beneficiaries in Home and Community-Based Settings who Exhibit Unsafe Wandering or Exit-Seeking Behavior*, Dec. 15, 2016, at 3, available at <https://www.medicare.gov/federal-policy-guidance/downloads/faq121516.pdf>.

Any setting using controlled-egress should assess an individual that exhibits wandering (and the underlying conditions, diseases or disorders) and document the individual’s choices about and need for safety measures in his or her person-centered care plan.”

The guidance is available at: <https://www.medicaid.gov/federal-policy-guidance/downloads/faq121516.pdf>

ii. Community integration

A second issue that has been raised is how to promote community integration for people who are at risk of unsafe wandering or exit-seeking. In its FAQs, CMS states:

All settings must facilitate and optimize Medicaid beneficiaries to live according to their daily routines and rituals, pursue their interests, and maximize opportunities for their engagement with the broader community in a self-determined manner, as outlined in the individual’s person-centered service plan. The plan must reflect clinical and support needs as identified through an assessment of functional need, and document the individual’s preferences for community integration and how these preferences will be addressed in the setting they have chosen.³⁵

CMS identifies a number of strategies and practices to support community integration, including the following:

Providing sufficient staff and transportation to enable individuals’ participation in their activities of choice in the broader community. These could include opportunities for work, cultural enjoyment, worship, or volunteering. The person-centered service plan may also include provider-facilitated opportunities to engage in desired activities in the broader community.³⁶

iii. Advocacy opportunities

- Urge the state to subject all memory care settings to heightened scrutiny since these settings have many of the isolating characteristics identified by CMS
- Advocate for the state to thoroughly investigate the following issues when gathering information for heightened scrutiny from memory care settings:

³⁵ *Id.* at 6.

³⁶ *Id.* at 7.

- If the setting uses controlled egress, were other options explored for each individual before any modifications occurred to their person-centered plan (as indicated in the CMS FAQs)?
- Have the same modifications been made for everyone? Are person-centered plans identical instead of being tailored to the needs and preferences of each person?
- Is there documentation that individuals have been asked if they would like to participate in activities in the community either by themselves with support and assistance or in a group? If the person would like to do so, what has the provider done to make that happen? Does staff escort the individual to locations and activities outside of the setting?
- If the setting asserts that HCBS beneficiaries can participate in community activities of their choice, is sufficient staff and transportation provided?
- Evaluate evidence for any memory care setting submitted for heightened scrutiny review in which clients receive services. As noted in the earlier discussion about heightened scrutiny, assess whether the information is accurate based on client information/experience and whether the evidence shows that the setting has the necessary home and community-based characteristics. Submit written comments to the state and CMS.

Evictions

The HCBS requirements state that for any provider-controlled or owned residential setting, the resident must have protections equivalent to those provided to the state's rental tenants. If the state's landlord-tenant law does not apply to the setting, the setting and resident must enter into a written agreement that establishes equivalent protections.³⁷

To come into compliance with this HCBS settings requirement, the majority of states are simply incorporating the HCBS rule language verbatim into rules, provider contracts and/or policy manuals.

On the positive side, advocates have long been concerned about inadequate safeguards against the eviction of assisted living facility residents. In a number of states, individuals have few to no transfer/discharge rights under state regulations and can be evicted with little notice and no opportunity to appeal. The HCBS requirements mean that for the first time many residents in assisted living facilities with Medicaid funding will receive at least some very minimal eviction rights and protections.

³⁷ 42 C.F.R. § 441.301(c)(4)(vi)(A)

However, the HCBS rule based on state landlord-tenant laws does not provide the level of protection and rights that residents need. State landlord-tenant laws are inadequate for a number of reasons:³⁸

- Laws in several states allow for evictions without cause.
- The justification for evictions in most laws do not reflect that the “landlord” may also be providing services supports and care.
- The amount of notice required – generally 3-7 days - is insufficient for frail, dependent individuals. Across studies examining relocation-related stress and transfer trauma, it appears that time spent preparing residents for a move reduces negative consequences and supports successful adjustment.
- The only way to appeal is usually to go to court, which can be difficult and overwhelming for many residents.

i. Advocacy opportunities

As noted earlier, the “gold standard” for systemic remediation is revising state licensure regulations. Whenever possible, elder law attorneys should advocate for the state assisted living regulations to be changed to increase resident transfer/discharge protections and rights.

Both Oregon and Montana have existing state licensure regulations that include important eviction protections.³⁹ Elder law attorneys should advocate for similar protections in their states.

Oregon:

- Assisted living regulations allow for eviction only under seven specific conditions.
- Eviction can be challenged through administrative hearing.
- Resident protections must be addressed in residency agreement.

Montana:

- Transition plan points to existing state regulations.
- Only five justifications for eviction.
- Right to administrative hearing.

³⁸ Carlson, Eric, Justice In Aging, *How States Can Prevent Evictions When Implementing Federal HCBS Regulations*, Aug. 2017, available at <http://www.justiceinaging.org/wp-content/uploads/2017/08/How-States-Can-Prevent-Evictions-When-Implementing-Federal-HCBS-Regulations.pdf>.

³⁹ NASUAD HCBS Conference Session: *Growth and Uncertainty in HCBS-Funded Assisted Living*. Powerpoint presentation. Eric Carlson. August 29, 2017

For more information and analysis, see *How States Can Prevent Evictions When Implementing Federal HCBS Regulations* by Eric Carlson of Justice in Aging: <http://www.justiceinaging.org/wp-content/uploads/2017/08/How-States-Can-Prevent-Evictions-When-Implementing-Federal-HCBS-Regulations.pdf>

CONCLUSION

An important part of the practice of many elder law attorneys is assisting clients to receive and then benefit from Medicaid home and community-based services (HCBS). In March 2014, the Centers for Medicare and Medicaid Services (CMS) published the first ever regulations setting standards for the settings in which HCBS are provided. These rules will impact the services, quality of life, and rights of HCBS participants, as well as the environment in which they receive those services. Each state must develop and implement a plan for how it will come into compliance with the HCBS rules. The involvement of advocates, including elder law attorneys, in influencing the plan and monitoring its implementation is critical. This guide is designed to provide elder law attorneys with a better understanding of the HCBS settings rule and how they can advocate for a strong, effective system that achieves the spirit and intent of the rule.

The goal of the HCBS settings rule is to enhance quality in HCBS programs, add protections for individuals receiving services and ensure that those individuals have meaningful choices and full integration into the community. But rules are not self-implementing. Without strong advocacy, the settings rule will not achieve its promise. By gaining more knowledge about the HCBS rule and selecting the advocacy strategies presented in this guide that are best suited to their state, elder law attorneys can play an important role in shaping the HCBS system in a way that improves the lives of their clients.

