

Created by the HCBS Advocacy Coalition

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1. Introduction

In January 2014, the federal agency that oversees the Medicaid program, the Centers for Medicare & Medicaid Services (CMS), announced new rules that created standards for Medicaid-funded home and community-based services (HCBS). In this document, we refer to these new rules as the "HCBS settings rules," "settings rules," or just "rules." Each state has until March 2022 to fully follow these rules. The rules can be a game-changer to promote integrated residential and day service settings in Medicaid. People from all over the country sent in thousands of public comments when the rules were being created, and the comments reflected a wide range of points of view. The whole process took over five years to complete. The final rules, which took effect in March 2014, require that all HCBS settings must:

- Be integrated in and help provide full access to the greater community;
- Improve self-determination and independence in making life choices;
- Be chosen by the individual from among residential and day options, including settings that are not only for people with disabilities (called "non-disability specific settings");
- Make sure of the right to privacy, dignity, respect, and freedom from coercion and restraint;
- Provide an opportunity to work in a typical job in the community (called

- "competitive integrated employment");
- Provide people with an option to choose a live in their own unit or bedroom in the place where they live (called a residential setting); and
- Make sure there is a choice of services and providers.¹

The rules have additional requirements for settings where the same person or organization owns the place where someone lives and provides them services (called "provider-owned residential settings").

The rules repeat the federal law that institutions (such as nursing homes, psychiatric hospitals, or intermediate care facilities for individuals with intellectual disabilities (ICF/IDDs)) are not allowed to receive Medicaid HCBS money and instead get money for institution.² The rules also describe settings that are likely to have the qualities of an institution, called "settings presumed to be institutional." Unless a state provides evidence that such a setting actually meets all the standards in the rule, it cannot receive Medicaid HCBS money. For places with institutional qualities, there is an extra review process called "heightened scrutiny." The rules also explain detailed person-centered planning requirements for all HCBS programs.³ Importantly, the rule focuses on the person's experience in a setting and requires that they can go out into their community just like their neighbors who are not receiving Medicaid HCBS.

To make sure that the transition was smooth for people already receiving services, the rules allow for a long transition over a number of years (now until March 2022.) This gives states time to put the new rules in place and make sure settings make all the needed changes to follow them.⁴

Necessary changes will occur over several years, and the rules include protections for people receiving HCBS services who might move to new, more integrated settings. In other words, the changes will not cause people to lose access to services and supports in their individual plan.

People will not lose access to services and supports in their individual plan because of the HCBS changes.

States must create a plan to follow the rules while making sure services continue uninterrupted. They do this through a statewide transition plan, or STP. The public has a chance to look at the STP and make comments about what they do and do not agree with. CMS must review and approve the state's plans.

2. Why are these recent HCBS rules important?

States have until March 2022 to comply fully with the HCBS settings rules.¹ Advocacy is needed throughout the transition!

These rules are important because they support the inclusion and integration of people with disabilities in the community. They build on decades of prior work, including major federal disability rights laws like the Americans with Disabilities Act, the Rehabilitation Act, the Developmental Disabilities Act, and the Individuals with Disabilities Education Act. Having these policies in the settings rules will push state systems closer to the goal of truly person-centered practices, full inclusion, and integration in the community.

3. Why is state-level advocacy around these rules important?

For the rules to make positive change, states will have to work hard to implement the rules and the federal agency overseeing the rules (CMS) will have to make sure states are following the rules. The strength of each state's statewide transition plan (or "STP") comes from early, consistent and meaningful conversations with a wide

range of stakeholders, advocates, and people receiving Medicaid HCBS.

It's important to be involved now because states are making important decisions to evaluate their HCBS settings. CMS has said that they are looking closely at public comments — advocates' voices matter!

The HCBS Advocacy coalition, a group of national advocacy organizations committed to improving community integration opportunities for people with disabilities, has prepared many resources to help advocates and stakeholders get involved in their STP development. These resources are available at https://HCBSadvocacy.org/

4. What role do advocates and stakeholders play in a state's transition to follow the settings rule?

The role of advocates is to make sure that their community is active and paying attention to their state's transition. The rules' potential to positively change HCBS systems will only happen if advocates and stakeholders give their feedback on their states' efforts to follow the rules. The process offers many opportunities to provide input, therefore advocates should track upcoming public comment opportunities and be prepared with information.⁵

Public comment is key. The rules require all states must provide at least one 30-day opportunity for public comment on the STP. States must hold an additional public comment period for any "substantive" changes to their plan, such as changing any timelines, deciding whether a setting meets the rule, or submitting settings to CMS through the heightened scrutiny process.⁶

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times during the transition period. States will have to update their state plans several times during the transition period. Even after CMS approves a state's final STP, advocates and stakeholders will have additional opportunities for public input, including if a state makes changes to its Medicaid HCBS program (though what is called waiver amendments); changes state rules, policies, and procedures related to the HCBS programs; changes to state statutes or code; or identifies settings for heightened scrutiny.

5. Which Medicaid programs are covered by the new HCBS rules?

The rules apply to all settings funded through the major Medicaid HCBS programs. This includes settings funded through 1915(c) waivers (generally known as "waiver programs"); state plan home and community-based services offered through 1915(i) and the 1915(k)

Community First Choice state plan options; 1115 demonstration waivers; and HCBS provided under 1915(b)(3) managed care programs.

The rules do not apply to settings funded under non-HCBS programs, such as general state plan services, although states may choose to apply the same standards to these services as well.

6. What are states supposed to do in order to follow the rules?

All states have until March 2022 (extended from the original March 2019 deadline) to fully meet the standards created by the rules. States must work with CMS to finalize a statewide transition plan (or "STP"). This is a three-step process. Each of the three steps provide advocates and stakeholders with the opportunity to give public comment.

Initial STP approval

The state submits the STP to CMS for review and initial approval. In the STP, the state must evaluate all related state regulations, licensing requirements, and other policies to make sure they support the rule and to identify gaps in state policies. This "systemic assessment" must include suggested revisions and a timeline for making for needed changes to meet all the rules' requirements.

The STP must also describe the process for states to assess existing HCBS settings, to validate those assessments, and to

identify "presumptively institutional settings."

Final STP approval

After initial approval, CMS sends the state a letter detailing other necessary changes to complete its STP. After revisions and more public comment, the state submits the revised STP to CMS for review and final approval. CMS reviews and approves:

- The process for assessing and validating whether settings meet the rules' requirements; and
- The process for identifying "presumptively institutional settings" and for determining whether those settings actually can meet the rules' requirements (known as "overcoming the presumption")

The STP should include information on how to the state will fix any settings that have problems, talk about continued monitoring, and create a relocation process to make sure people who move to new settings have no problems continuing their services.

Heightened scrutiny review process

The heightened scrutiny review can occur at any point in the process – it doesn't depend on STP approval. It involves two steps. First, the state identifies and evaluates settings presumed to have characteristics of an institution. (See question 12) The public can also help identify such settings directly to CMS.

Second, the state submits a list of the "presumed institutional" settings that it believes actually follow all the settings rules. It includes a package of evidence it has collected that shows how the setting is not institutional, but actually community-based. The state's evidence should include on-site visits and/or interviews with people receiving services in those settings. Before submitting to CMS, states must get input from the public about the heightened scrutiny evidence packages.

So far, the amount and detail of information provided in STPs have varied widely. CMS has sent many plans back for revisions, explanations, and more public comment opportunities. Many states have revised their plans several times, with more to come. Each revision to the state plan with big changes requires a new round of public comment. Unfortunately, several states are lagging far behind in their approval process.

CMS continues the process of reviewing state transition plans. As of March 2019, 42 states received initial approval on their STPs and 13 have final approval.⁷

7. Which HCBS settings does the rule cover?

The rule applies to all settings that get Medicaid money through HCBS programs, including settings where people receiving services live (called "residential settings") and where they get services during the day (called "non-residential settings"). This includes settings such as group homes,

day programs, employment options, and other independent living situations. Provider-owned or controlled residential settings, such as group homes and assisted living facilities, have to follow additional requirements (see Question 8).

States have to design a process to monitor HCBS settings to make sure the setting keeps following the rules even years after they get approved. All of these new standards, if properly put into place, can make HCBS better, give people receiving HCBS basic rights, and increase opportunities for people with disabilities to fully engage in community life.

8. How do the rules affect provider-owned or operated residential settings?

The rules do not prohibit provider-owned or operated settings (where the same person or organization owns the setting and provides services), such as group homes. However, in addition to meeting the general rules about community integration and the rights of people receiving Medicaid HCBS, these residential settings must make sure that participants have these additional protections and rights:

- A lease or other legally enforceable agreement to protect from someone being kicked out or evicted from where they live;
- Privacy in their unit including entrances lockable by the individual (necessary staff may have keys as needed);

- Choice of roommates, including the option of a private unit;
- Ability to furnish and decorate their unit;
- Control of their daily schedule and activities;
- Access to food at any time;
- Visitors of their choosing at any time; and
- Physical accessibility for the individual.

If a provider limits any of these protections and/or rights, they must write the reason down in the individual's person-centered plan. Limits can only be based on a need that is about the specific person, must include a clear description of the restriction that is directly related to the specific assessed need, include the permission (called informed consent) of the individual, and have a set end point for the change, including periodic review.8 The personcentered plan must also include less restrictive options that had been tried, list the positive interventions and supports used prior to any change, promise that no harm will come to the individual from the changes, and include regular collection and review of data to determine the effectiveness of the change.

Some disability-specific, provider-owned, or group settings may be similar to "settings that isolate" (see the following question). If states identify such settings, they must describe in their STPs whether

these settings will continue to be eligible for Medicaid HCBS, and if so, how these settings will update their practices to meet the revised HCBS standards.

9. Do the HCBS settings rules apply to non-residential settings?

Yes. The HCBS settings rules apply to all settings paid through the Medicaid HCBS programs listed in Question 5 — both residential and non-residential. CMS created a set of "Exploratory Questions" to help states evaluate non-residential settings, all non-residential settings must meet federal and revised state standards for providing participants opportunities to be a part of community life, to have access to the community, to control their personal resources, and to look for jobs and work in competitive integrated employment just like their neighbors.

States must evaluate any non-residential settings, including employment settings and day programs, using the same rules that apply to other settings. This includes identifying anything that isolates participants from the larger community. In other words, do participants have the same level of access to their community as people who do not receive Medicaid? If not, the state must show how the setting's isolating qualities will be fixed during the transition process. CMS has also noted that pre-vocational services need not be facility-based and may be offered in a variety of settings in the community.

10. Are certain institutions like hospitals or nursing homes covered by the rules?

No. The HCBS rules make clear that institutions like hospitals, nursing homes, Institutions for Mental Disease or ICF/IIDs cannot be considered HCBS settings. This has always been the law and the HCBS rules did not change that. Other settings not specifically listed as institutions may be so similar to institutions in how they operate that they do not meet the standards of an HCBS setting. Instead, HCBS programs are an alternative to institutional services. Institutional services have never been allowed to receive Medicaid HCBS funds and have their own Medicaid funding streams that come with different requirements.

11. How do states determine if a setting meets the HCBS requirements?

All HCBS settings must show they follow all the rules. One of the first things states have to do is evaluate providers/settings to see if they are completely following the regulations. Knowing what needs to change is important for developing the state's STP and identifying where states need to focus attention.

States make an initial assessment of its current HCBS settings and categorize each into one of four categories:

1. Settings that completely follow the HCBS requirements;

- Settings that cannot meet the HCBS requirements and should be removed from the HCBS program and/or the relocation of individuals:
- 3. Settings that are not following the HCBS requirements and will need to make changes; or
- 4. Settings that are *presumed* to have institutional qualities, but for which the state will provide evidence through the *heightened scrutiny* review (discussed in question 11) to show the setting actually has all the qualities of HCBS settings.

For any setting that falls under categories 3 or 4 that want to continue providing Medicaid HCBS, a plan to fix the problems must be developed and completed before the end of the transition period. The plan must include how the problems will be fixed and how the state will make sure all those fixes have been made. The plan and the initial assessment must be available for public comment. Advocates, who know how settings really work, are very important to a correct evaluation of the HCBS settings.¹⁰

12. What types of settings are presumed to be institutional?

The rule identifies the following settings as presumed to be institutional:

 Settings in a building that is also a publicly or privately-owned facility that provides inpatient treatment (like a nursing home or hospital);

- Settings on the ground of, or immediately adjacent to, a public institution (like a state-operated facility for people with developmental disabilities called an Intermediate Care Facility); and
- Settings that have the effect of isolating people receiving Medicaidfunded HCBS from the broader community of individuals not receiving Medicaid-funded HCBS.

All settings will be reviewed individually by the state to determine if they fall into one of these categories and they need to follow the *heightened scrutiny review* for approval.

The first two types of settings are relatively easy to identify, but the last category of "settings that isolate" is less concrete and more focused on how what it's like for people to live or spend time in the setting. States may choose to not have CMS review presumptively institutional settings for heightened scrutiny, and instead develop plans to transition individuals to more integrated settings that do follow the HCBS rules.

To evaluate whether a setting has the effect of isolating people, CMS looks at several factors, ¹¹ focusing on how the setting location and programming affects participants. These include looking at if:

 Due to the design or model of the way services are provided in the setting, people have limited, if any, opportunities¹² for interaction in and with the greater community,

- including people not receiving Medicaid-funded HCBS;
- The setting restricts the person's choice to receive services or to participate in activities outside of the setting; or
- The setting is located separate and apart from the greater community without giving the participant the opportunity to access the greater community and participate in community services, consistent with their person-centered plan.

States can also identify additional factors beyond this list, but the state needs to be clear any additional factors of isolation so that stakeholders have a clear understanding of what the state considers isolating.

If a setting meets the criteria for isolation of HCBS participants but fixes the situation by July 1, 2020, the state doesn't need to submit that setting to CMS for a separate heightened scrutiny review. But the setting should be identified in the STP for public comment and/or identified in the information disseminated separately from the STP for public comment. CMS can also review any setting if significant public comment disagrees with the state's assessment, so stakeholder comments and participation in the process are extremely important.

13. What is "heightened scrutiny" review?

As part of the initial assessment, states must flag settings that have some institutional qualities (like institutional size, practices, and/or physical connection with an institutional setting). If the state believes the setting can (and should) meet the HCBS standards after making changes, it may provide evidence to CMS through a process called "heightened scrutiny." CMS then decides if the evidence shows the setting overcomes the institutional qualities and meets the rules for being communitybased. If a setting initially put on the list of settings presumed to isolate people fixes all its problems with following the HCBS rules by July 1, 2020, and if the state verifies that the setting now follows all the rules, that setting will not have to go through a full heightened scrutiny review. However, states must include all the isolating settings that fixed their problems in the STP (or in another notice) and post that list for public comment. Advocates should pay attention to this list and tell their state if certain settings are more institutional than the state says they are.

CMS created a set of "Exploratory Questions" to help states find out if settings follow all the rules. Though states perform the assessments, CMS has to make the final decisions on which settings to approve based on the evidence states provide. Evidence should focus on how the setting helps people receiving Medicaid HCBS to be involved in and access the greater community as they would like. It

should not focus the qualities and/or extent of the disabilities of the people served in the setting.

The state's STP must include information about both the settings flagged as isolating but that fixed their problems prior to July 1, 2020 as well as the settings flagged as presumptively institutional that have not fixed their problems yet but will go through heightened scrutiny. For heightened scrutiny settings, the state must include evidence packages for settings it determines meet the rules' requirements. The public must have a chance to comment on the list and on the evidence and may also identify any settings that they believe should have been, but were not, identified as presumptively institutional.

The state should also include any feedback received during the public comment period for these settings. In addition to the information provided by the state, CMS also considers information provided directly from other people and organizations.¹⁴

14. Can a state apply higher standards for HCBS settings than the rules require?

Yes. The federal HCBS settings standards establish the minimum requirements for what is considered a community setting. A state may require higher standards. For example, a state may decide that it only wants to use HCBS funds to support competitive integrated employment for HCBS participants and may choose not to

fund settings with more segregated services, such as sheltered workshops. Although all states have to make sure every HCBS setting meets the minimum federal requirements, CMS has allowed states flexibility in how they apply more strict HCBS standards. A state may decide to stop new admissions or stop approvals for new providers for certain types of settings. Or a state could temporarily stop authorizing settings that only meet the minimum standards while establishing stronger standards for all new settings. A state may continue this practice, referred to by CMS as "tiered standards," to promote settings that satisfy the state's higher standards.

States that plan to use tiered standards must describe their approach in the state's STP. This flexibility allows a state to slowly phase out certain settings or provider types as it increases more integrated community-based settings and services.

15. What happens to people receiving services in *non-compliant* settings? Will they lose services?

No. Under no circumstances will participants be left without services as a result of the rule. States have until March 2022 to completely follow the settings rules. Hopefully, most settings will follow the settings rules and the process described in the state's STP. However, there may be some settings that – because of the location of the setting, the setting's

programs, or other reasons – will not completely follow the rules by the deadline. If the state finds that it will need to stop providing HCBS money to certain settings, the STP must describe the process for transitioning participants into settings that meet the HCBS requirements. The process must detail how the state will protect individuals' rights, provide adequate notice, give people choices of other settings that meet the rules, and make that services are not interrupted during the transfer. States must allow enough time to transfer everyone who may need it.

Or the state may require that the provider change their type of Medicaid funding by becoming licensed as an institution, like an intermediate care facility or nursing home. States may need to train providers on how to replace any settings that cannot meet the requirements under the settings rules and make sure that all HCBS participants are offered a choice of non-disability specific settings.

16. Do the HCBS rules affect provider choices for HCBS participants?

In addition to participants having a choice among providers – already a requirement for HCBS services – the new rules require that HCBS participants must also be offered a choice of a non-disability specific setting as part of their person-centered planning process. A non-disability specific setting is a setting that is not only for people with disabilities. One example of non-disability services settings would be a

person living and receiving services in his or her own apartment or home instead of a group home. Another is working and receiving employment supports in a typical job in the community instead of in a sheltered workshop. STPs will need to provide information and trainings on how to increase the number of providers of certain types of services so that people are offered a choice of residential and day services in non-disability specific settings.

For more information about the HCBS settings rules, see:

- https://HCBSadvocacy.org/ or
- https://www.Medicaid.gov/medicaid/ https://www.Medicaid.gov/medicaid/

HCBS Advocacy Coalition & Contact Information HCBS Advocacy Coalition

Website address: http://hcbsadvocacy.org/
Email address: hcbsadvocacy@gmail.com

The HCBS Advocacy Coalition is a voluntary association of the following organizations working together to advance state compliance with HCBS setting requirements:

American Civil Liberties Union

American Network of Community Options and Resources

Association of People Supporting Employment First

Association of University Centers on Disabilities

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

Center for Public Representation

Council on Quality and Leadership

Collaboration to Promote Self-Determination

Human Services Research Institute

Justice in Aging

National Association of Councils on Developmental Disabilities

National Consumer Voice for Quality Long Term Care

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National Council on Independent Living

National Disability Rights Network

National Down Syndrome Congress

National Health Law Program

National Leadership Consortium on Developmental Disabilities

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The Arc of the United States

¹ See generally Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, <u>79 Fed. Reg. 2948</u>, 3030-31 (Jan. 16, 2014) (to be codified at 42 C.F.R. § 441.301(c)(4)).

² Intermediate Care Facilities (ICFs) are Medicaid funded and licensed institutions for individuals with intellectual disabilities. They range from large state-operated facilities to smaller privately-operated facilities.

³ This FAQ is focused on the parts of the rule describing requirements for HCBS settings.

⁴ CMS, CMCS Informational Bulletin1 (CIB-01-10-14).

⁵ Stakeholders and advocates can find information about the state's transition process at http://www.HCBSadvocacy.org/, at www.medicaid.gov/medicaid/hcbs, and on the state's website. Some states divide their HCBS settings work across several departments. Advocates should ask to be added to any listservs the state may use to provide updates on its HCBS transition. This could include listservs generally targeted to Medicaid recipients, providers, or those tracking all administrative rule changes. Most of the STPs plans have timelines that indicate when the state expects to have public comment opportunities and these dates should be on advocates' calendars. Well before public comment periods, advocates should gather information regarding such issues as settings that should be phased out, state rule changes that need to take place, barriers to implementation, and ongoing monitoring and quality assurance.

6 See, e.g., 42 C.F.R. § 441.710(a)(iii) (requiring 30-day public comment period for the initial plan); see also CMS, Statewide Transition Plan Toolkit for Alignment with the HCBS Final Regulation's Setting Requirements 7 (Sept. 5, 2014); CMS, Steps to Compliance for HCBS Settings Requirements in a 1915(c) Waiver and 1915(i) SPA, (noting that the public comment process must be used when a plan undergoes a substantive change).

7 See the state of state terms if a number of state terms if number of state terms if a number of state terms if a number of s

⁷ See the status of state transition plans, including any letters from CMS, on the <u>CMS Statewide Transition Plans</u> website at https://www.medicaid.gov/medicaid/hcbs/transition-plan/index.html
⁸ See, e.g., 42 C.F.R. § 441.301(c)(4)(vi)(F). Physically accessibility may not be modified in the person-centered planning process.

⁹ For more information on settings, see the following resources from CMS: Exploratory Questions on Residential and Non-Residential settings.

¹⁰ See http://HCBSadvocacy.org/ for advocacy tools and other resources.

¹¹ See, CMS, <u>The HCBS Heightened Scrutiny Frequently Asked Questions (FAQs)</u> (March 22, 2019), SMD # 19-001.

Opportunities, as well as identified supports to provide access to and participation in the broader community, should be reflected in both individuals' person-centered service plans and

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the policies and practices of the setting. The HCBS Heightened Scrutiny Frequently Asked

Questions (FAQs) at 1.

13 See Exploratory Questions, *supra* note 8.

14 Individuals can submit public comment directly to CMS through email at hcbs.gov. One effective window is after a state has responded to public comments in a revised STP. Advocates can provide additional information on topics the state did not respond to or decided not to change.

¹⁵ For more information, see Joint Statement by NASDDDS, ANCOR and Disability and Aging Groups Regarding Continuity of Services during Implementation of the HCBS Rule.