



The Home and Community Based Services Settings Rule

The ACLU and the HCBS advocacy coalition strongly supports implementation of the Home and Community Based Services (HCBS) Settings Rule because it is a vital part of the broader effort to promote community integration for people with disabilities. People with disabilities deserve the same rights to make choices, access the broader community and interact with the broader world as anyone else. The HCBS Settings Rule helps support that outcome.

The HCBS Settings Rule is a tool for promoting full access to community life. As federal policymakers have worked to help people with disabilities leave institutions and other segregated settings, it has become more important to have clear standards in place indicating which settings are in the community and which are more appropriately considered to be institutions. The HCBS Settings Rule ensures that people with disabilities have access to truly integrated alternatives to the regimentation and isolation of institutional life. As a result, the HCBS Settings Rule is a natural complement to the Americans with Disabilities Act and represents a critical component of full community integration for people with disabilities of all kinds.

Frequently Asked Questions

What is the Home and Community Based Services (HCBS) Settings Rule?

In 2014, the Centers for Medicare and Medicaid Services (CMS) at the Department of Health and Human Services issued the HCBS <u>Settings Rule</u> to require that every state ensure that services delivered to seniors and people with disabilities living in the community – outside of institutions – meet minimum standards for integration, access to community life, choice, autonomy, and other important consumer protections.

The HCBS Settings Rule was created to expand the availability of community-based services that maximize autonomy and choice for individuals with disabilities, and to address the problem of institutional-like settings receiving scarce HCBS dollars.

Why is the HCBS Settings Rule needed?

As states have worked to support people with disabilities to leave institutions and enter the community, many have struggled to define the differences between these two experiences. Some providers may bill themselves as "community-based" while replicating the underlying restrictions and isolation of the institution.

The HCBS Settings Rule was put in place because of concerns that many states and providers were using federal dollars dedicated to community-based supports to pay for disability services that were still institutional in nature. Too many of the so-called "community" options were exercising the same control and isolation over individuals as larger institutions. By articulating a set of minimum requirements for HCBS funding, the Settings Rule ensures that federal funds are used for their intended purpose and that individuals with disabilities have an opportunity to enjoy

the autonomy and freedom associated with community life.

What does the HCBS Settings Rule require?

The rule applies to all settings (i.e. place where seniors and people with disabilities live, work, or spend time) that receive HCBS funding, and requires that the setting:

- is integrated in the greater community;
- supports the individual's full access to the greater community, including opportunities to seek employment, work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community;
- is selected by the individual from among different setting options, including nondisability specific options and an option for a private unit in a residential setting;
- ensures an individual's rights to privacy, dignity, respect, and freedom from coercion and restraint;
- optimizes individual initiative, autonomy, and independence in making life choices, including in daily activities, physical environment, and personal associations; and
- facilitates individual choice regarding services and supports and who provides them.

The requirements are designed to ensure that people with disabilities living in the community have access to the same kind of choice and control over their own lives as those not receiving Medicaid HCBS funding.

What does the HCBS Settings Rule require of a "provider-owned or controlled residential setting"?

A "provider-owned or controlled residential setting" is one in which the service provider also owns or controls the real estate where the individual lives, as distinct from a setting owned or controlled by the person receiving services or their family where the provider merely arrives to deliver support services. Here, some additional requirements apply. This is because research shows that these settings are more likely to limit residents' rights – in part due to the inability of residents to fire their service provider without having to move to a new home. Individuals in these settings must:

- Have a lease or other legally enforceable agreement providing similar protections;
- Have privacy in their unit, including lockable doors, choice of roommates and freedom to furnish or decorate the unit;
- Have the right to control his/her own schedule including access to food at any time;
- Have the right to visitors at any time; and
- Have a setting that is physically accessible.

Exceptions can be made to these requirements if supported by a specific need that is justified in the individual's person-centered service plan – but this must relate to the individual, not the facility. For example, if a resident has Prader-Willi Syndrome, a condition associated with a dangerously uncontrollable appetite, access to food may be restricted based on safety considerations documented in the resident's plan. However, a facility may not have rules for all residents on when mealtimes occur or what residents may eat.

What is "heightened scrutiny" and what settings must pass it?

Some settings are "presumed to have institutional qualities," including those in a facility that

provides inpatient treatment; those on the grounds of, or immediately adjacent to, a public institution; and those that "have the effect of isolating individuals receiving Medicaid-funded HCBS from the broader community of individuals not receiving Medicaid-funded HCBS."

With these settings, the state must apply for special permission from CMS to use HCBS funds and undergo a process called "heightened scrutiny." The process requires the state to show that the setting is truly home and community-based and does not have the qualities of an institution. The state must open a public comment process to stakeholders to collect relevant information so that the state and ultimately CMS can determine whether or not the setting may be funded with HCBS.

What are settings that "have the effect of isolating individuals"?

CMS has issued <u>guidance</u> on what kinds of settings fall into the category of those that "have the effect of isolating individuals receiving Medicaid-funded HCBS from the broader community." The guidance explains that these settings are typically designed specifically for people with disabilities (or even people with a certain type of disability). In such settings, the individuals residing within them are primarily or exclusively people with disabilities. They may be designed to provide people with disabilities with many services and activities on-site, and to offer limited, if any, interaction with the broader community. They may authorize the use of unacceptable interventions such as seclusion.

CMS has offered a non-exhaustive list of residential settings that isolate, including disabilityspecific farmsteads or farm communities, gated or "secured" communities for people with disabilities, residential schools, and settings where multiple services are co-located and operationally related and that congregate large numbers of people with disabilities together.

Does the HCBS Settings Rule apply to non-residential services?

The HCBS Settings Rule applies to all HCBS-funded programs, including non-residential services such as day and employment supports. States should require these programs to promote greater integration. This includes serving people in the same environments in which non-disabled people work and engage in recreational activities as well as offering individualized, rather than program-wide, schedules for program participants with disabilities. The rule also requires settings to work to provide opportunities for competitive integrated employment for people with disabilities.

When must states comply with the HCBS Settings Rule?

States have until March 17, 2022 to comply with the Settings Rule. The original deadline was March 17, 2019 but it was extended in May 2017 by CMS.

When doesn't the HCBS Settings Rule apply?

The HCBS Settings Rule does not apply to institutional care funded through Medicaid's three institutional funding authorities: Skilled Nurse Facilities, Intermediate Care Facilities for Individuals with Intellectual Disabilities and Institutions for Mental Diseases. Only services funded with Medicaid HCBS dollars are subject to the HCBS Settings Rule.

How do states comply with the HCBS Settings Rule?

States must submit Settings Transition Plans to CMS, stating how the state will reach full compliance with the HCBS Settings Rule and identifying milestones for compliance. Each plan must undergo public comment within the state. CMS provides feedback on each plan, and seeks to approve all plans by March 17, 2022.

What can advocates do to make sure their state complies with the HCBS Settings Rule?

Each state must provide opportunities for public comment on its Settings Transition Plan on multiple occasions. States are also required to seek public comment for any heightened scrutiny request. Advocates should participate in these public comment opportunities to show their support for integrated services and settings, and for state compliance prior to the 2022 deadline.

Advocates should also look at their state transition plan and the CMS Exploratory Questions for <u>Residential</u> and <u>Non-Residential Services</u> to help evaluate how well their state is doing at coming into compliance. These can be found at <u>https://www.medicaid.gov/medicaid/hcbs/guidance/index.html</u>.

Does the HCBS Settings Rule limit choice for Medicaid beneficiaries?

No it does not. The HCBS Settings Rule expands choice by requiring states to offer more individualized, non-disability-specific settings. The rule introduces a new requirement that states offer people a choice of non-disability-specific settings, expanding the options available to individuals with disabilities. While the HCBS Settings Rule makes it more difficult for some kinds of settings to be funded as HCBS, these settings can still be funded as institutions. The HCBS Settings Rule does not prevent people with disabilities from accessing congregate or institutional care through institutional benefits (Skilled Nursing Facilities, Intermediate Care Facilities for Individuals with Developmental Disabilities, and Institutions for Mental Diseases). In fact, because of how Medicaid is organized, these institutional benefits do not have waiting lists; HCBS benefits often do.

How does the HCBS Settings Rule serve people with the most significant disabilities?

The HCBS Settings Rule requires that providers serve people with the most significant disabilities in a manner consistent with their right to choice, integration and autonomy. CMS has issued <u>guidance</u> on how to apply the HCBS Settings Rule to beneficiaries with a variety of types of challenging behavior, such as individuals who "exhibit unsafe wandering or exit-seeking behavior." As the guidance explains, the HCBS Settings Rule is flexible and permits modifications to many specific requirements when an assessed need is documented in the individual's person-centered plan. For example, while the rule prohibits provider-owned or controlled residential settings from limiting a resident's access to food, such a setting could impose such restrictions in response to a need documented within a person-centered plan that could not be met through less restrictive means, such as for an individual with Prader-Willi Syndrome, for whom unrestricted access to food would be life-threatening.

For more information, please contact Alison Barkoff, Director of Advocacy, at the Center for Public Representation at <u>abarkoff@cpr-us.org</u>, or Vania Leveille, Senior Legislative Counsel, at <u>vleveille@aclu.org</u>. You can also learn more about the Settings Rule at <u>https://hcbsadvocacy.org/</u>.

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