

THE HOME AND COMMUNITY-BASED SETTINGS RULE: WHAT DOES IT MEAN FOR YOU?

A home- and community-based services (HCBS) setting is where you live or where you receive services, either in your home or in the community. In January of 2014, the Centers for Medicare and Medicaid Services (CMS) published a rule that CMS worked on with other federal partners and stakeholders.

The rule defines the qualities of a “home and community-based setting” in terms of what states can ask Medicaid to pay for in their waivers and in some of their state plan services. This rule applies to both residential settings where you live and non-residential settings, such as where you work or where you go to a day program.

There are several parts to the rule. There are important things for people who are receiving services and their family members or representatives to know.¹

This document will summarize what states will be working on with CMS. They will cover:

- How does CMS define a home and community-based setting?
- What are NOT considered home and community-based settings?
- What is a setting that isolates?
- How does person-centered service planning relate to whether CMS considers that a setting or service meets the requirement of the rule?

¹ NOTE: This document is written using plain language. Some of the official terminology from the CMS rule has been changed to make it more understandable. This document does not reflect legal or CMS Official Guidance. For more information, visit CMS' website at www.Medicaid.gov/HCBS or e-mail questions to CMS at hcbs@cms.hhs.gov.

What ARE the qualities of home and community-based settings?

- The setting is integrated in and supports your full access to the community, including opportunities to work, participate in community life, control your money, and receive services in the community just like people who do not receive home and community-based services.
- You have chosen the setting based on your needs and preferences.
- The setting ensures your right to privacy, dignity and respect, and freedom from coercion and restraint.
- The setting enables you to take initiative, be independent, make choices about your daily activities, the people you spend time with and your environment.
- The setting supports you to choose your services and supports and who provides them to you.

If you live in a home owned or controlled by a provider:

- You have the same rights and protections from eviction as other tenants, can lock your door, and can decorate where you live within the terms of your lease or other legal agreement.
- You have the right to choose your roommate.
- You can control your schedule and activities, eat when you want, have visitors and can move around freely without barriers that could cause you to fall or trip, even if you are in a wheelchair or use a walker. Any changes that need to be made to the setting to ensure your health, safety and well-being must be thoughtfully considered and written into your plan with your input and agreement.

What is NOT considered a home and community based setting?

- A nursing facility
- An institution for mental diseases
- An intermediate care facility for individuals with intellectual disabilities
- A hospital
- Any other locations that have the qualities of an institutional setting, as

determined by the Secretary of Health and Human Services

What types of settings might be presumed to have the qualities of an institution?

- Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional care;
- Any building that is on the grounds or right next to a public institution;
- Any other setting that isolates you from people who are not receiving home and community-based services.

What is a setting that isolates?

- The setting is designed specifically for people with disabilities, particularly for people with a specific type of disability, and/or
- Everyone who lives there are either people with disabilities or the staff that provides services to them, and
- People have little, if any, interaction with the broader community.

Some examples of residential settings that may isolate:

- Farmstead or disability-specific farm communities where people live, work and rarely leave;
- Gated communities or campuses, where everyone lives on the campus and all leisure and work activities are on the campus;
- Residential schools;
- Groups of group homes close together in a single area.

If a setting or service looks or feels like it has the qualities of an institution and the state wishes to keep the setting in its HCBS program, the state will need to submit information to CMS to show that the setting really does have the qualities of a home and community-based setting. CMS will take a very close look at this information to see if it supports the state's claim. Based on this information, CMS can decide whether where you live and the services you receive really do have the qualities they expect in a home and community-based setting according to the rule, or they can ask the state to make changes. According to CMS, your

experience in the setting or service is important.

Your state should already have a process for person-centered planning.

- Your person-centered plan must show that you have had the opportunities to receive the type of home and community-based experiences that are described in the rule.

Sometimes, in order for a person with a disability to be well-supported and safe in the community, the state must make modifications to a person's setting. For example, some people may need more structured support. Some people cannot have unlimited access to food because of the risk to their health. But if you needed special supports where you live or receive services, it needs to be written into your plan under a special set of rules. These rules are:

1. The state must identify your specific and individualized need, and not make an assumption based on your diagnosis or type of disability.
2. The state must describe in the plan approaches that they already tried but didn't work
3. They must include a clear description of what they want to do in your plan and it must match what you need.
4. They have to collect information to see if the plan is working for you.
5. The state can only keep the changes in your plan as long as they are needed.
6. They must explain to you in language you can understand what the changes are, why they want to make the changes and you must say whether you agree to make those changes.
7. The state must make sure that the changes will not harm you.

How can you or your representative be involved as your state works to make sure all settings support people to have choices and be full participants in their communities?

Every state wrote a plan that reviews their settings and proposed how to change them if they needed to be improved. The plans had to be available for 30 days for everyone to read and think about. You may have sent in comments about this first plan. States are now finishing the reviews of their settings across the state, and they will be sending out information about what they found, and how they

will change the settings that do not follow the rules. You will have another chance to read the plan or have someone explain it to you, to see if it discusses where you live or where you get your day services. This report will say if the setting is following the rule, or if not, how the state needs to make improvements. You need to look at the state's Transition Plan again and tell the state agency if you like where you live and the services you are getting. If you are not happy and think things could be better, you should let the state know that too.

If your state does not seem to be following these rules, you should contact the state's Medicaid office or write to CMS at hcbs@cms.hhs.gov.

The success of the rule will be improved if the people who use services and their families or other people who care about them stay involved and let their state and CMS know if the state is following the Transition Plan they wrote. Advocates, families and stakeholders should communicate with their state often.

The following websites are posting information about the rule and your state's progress.

www.hcbsadvocacy.org and www.Medicaid.gov/hcbs.

It is important you know that states have 4 more years to work on their plans to change their services and settings to meet what CMS wants states to do. While states are working on this, as long as they show a good faith effort and show progress, CMS can keep funding the services that your state is providing.

YOU WILL NOT BE PUT OUT OF YOUR HOME OR LOSE SERVICES YOU ARE RECEIVING NOW.

You may be offered a change in your service or setting. You may want to stay where you are and keep what you have. States do have to make sure that the services and settings that they are providing to people meet the requirements of the rule. Any changes the state makes must maintain or improve the service or setting. If you want to move to another setting, or if the state feels that you would receive better services in another place, they must have a process in place to support you to choose another place to live or receive services, and you will be involved in the planning. CMS requires states to make sure people receive services in places that support them to have full access to their communities, a chance to work if they want to, supports their ability to make decisions about their activities, their money, what they eat and their schedules.

You can help your state and CMS be successful by staying involved over the next 4 years and letting the state know what you think.