

A National Connection for Self-Advocates



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Two Clicks - #1 Click on Resources then #2 Click on SARTAC Zoom Meetings

Background

- In March 2014 the federal government put out new rules for getting disability services.
- They are called Home and Community-Based Services (HCBS) settings rules.
- The final Rule is not perfect. CMS heard from a lot of different people. The Rule gave everyone some of what they wanted, but no group of people got everything they wanted. It was a compromise, but it is still a very important Rule.
- March 2023 is the deadline for states to follow the rules
- The part of the federal government in charge of the rules is called CMS or Center for Medicaid and Medicare Services

ASAN toolkit: This Rule Rules!: The HCBS Settings Rule and You

<https://autisticadvocacy.org/policy/toolkits/hcbsrule/>

This toolkit focuses on how the Home and Community-Based Services Settings Rule helps us live in the community.

- What is community living?
- What is an institution?
- What are home and community-based services (HCBS)?
- What does the HCBS Settings Rule say?
- What rights does the HCBS Settings Rule give me?
- What rules do HCBS providers have to follow?

What does the HCBS Rule do?

The HCBS Rule does a lot of different things. There are two main things it does:

- It gives people important rights.
- It makes providers follow rules in order to get HCBS money.

If a provider doesn't follow these rules, they can't get HCBS money. If a provider stops following these rules, they will lose HCBS money.

What rights does the HCBS rule give me?

If you get HCBS, the Rule says you have rights. You have the right to:

- Live in the community with people without disabilities
- Have a person-centered plan
- Have freedom
- Have respect and privacy
- Not be restrained or secluded.

Everyone can make choices.

- Some people might have a harder time showing other people what their choice is.
- They might not be able to speak.
- They might take longer to answer a question.
- They might need tools like an iPad or letterboard.
- They might not use words. They might show what their choices are with their actions.

This does not mean they can't make choices. It means we need to take more time and work harder to find out what their choices are.

All HCBS providers have to follow all of these rules. If they don't, they can't get HCBS money from Medicaid.

Sometimes, an HCBS provider owns the place where you get HCBS. For example, if you live in a group home or shared living provider. There are rules:

- Tenant rights
- Extra privacy rights
- Physical accessibility
- Controlling your everyday life
- Having Visitors
- Getting Food



Tenant Rights

People who rent houses are called **tenants**. People who own houses and rent them to someone else are called **landlords**. Tenants have rights. This makes sure landlords can't do unfair things to tenants.

The HCBS Rule says that in provider-owned settings, you are like a tenant. You get all the same rights as any other tenant, and your HCBS provider is like your landlord.

They can't do unfair things to you.



More Privacy Rights

Provider-owned settings have to do more to show they respect our privacy.



In provider-owned settings:

- You have to be able to lock the door to your room.
- Only roommates and in-home helpers can get the keys to your room or house.
- If you have a roommate, you get to pick your roommate.
- You can decorate your room or house any way you want.

Physical Accessibility

If you use a wheelchair, your house has to be wheelchair-accessible.

If you work in a provider-owned setting during the day, it has to be accessible. It does not matter what kind of disability you have. Providers have to make sure your house is accessible to you.



Right to Control Your Daily Schedule

You have the right to decide and do whatever you want to do every day. You get to set your own schedule. You get to decide how to spend your time. You get to decide where you want to go.



HCBS providers can't control how you spend your time. They can't force you to do something you don't want to do, like making you go to bed at a certain time. They have to follow your schedule.

Visitors At Any Time

You can always have visitors.

You can have visitors at any time. You can have visits from anyone you want. That means your friends, family, partners, or anyone else you want can visit. HCBS providers can't control what you do together while they are there. You can have people sleep over if you want.



Access to Food at Any Time

You can eat whatever you want in your house. You get to eat whenever you want to, even if it is late at night.

If you need help to get food, your provider has to help you. They can't make you only eat certain foods or make you only eat at certain times.



What do the states have to do to follow the HCBS Rule?

States have to make sure providers follow the HCBS Rule. All states have rules for providers. That means that the states all have to change their own rules, too.

States have to make a plan for how they will follow HCBS Rule. This is called an **HCBS transition plan**. States have to give this plan to CMS. CMS has to approve the state's plan before the state can use it.

Our rights don't go away.

Heightened Scrutiny

There are some places that can't follow the HCBS Rule. Institutions can never follow the HCBS Rule, so institutions can never get HCBS money.

Other places can follow the HCBS rule, but still look like institutions. States need to make sure these places aren't institutions before they give them HCBS money, or before they decide whether to continue giving them HCBS money. They do that by using something called **heightened scrutiny**.

Questions:

- 1. Are people in your states talking about the HCBS Settings Rule?**
- 2. Do self-advocates have the information they need to understand the HCBS Settings Rule?**
- 3. How is your state doing monitoring the providers to make sure they are following the rules?**
- 4. What can SARTAC do to help self-advocates learn about the rules?**