

Vermont Self-Advocates Want To Live With Everyone Else

Community living means living in the same places as people without disabilities. A community can be a neighborhood, town, or city.

Community living means having the right to make our own choices about our lives:



- where we go to work or school
- how we spend our free time
- what we want to eat
- how we decorate our homes + rooms
- who we make friends with
- who take care of us if we need help

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.



Background Information

- Many people with disabilities get services to live our everyday lives. Some examples are job coaches, transportation, and support staff that help you do things in your house.
- When we get services in their community, it is called home and community-based services (**HCBS**).
- 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**.

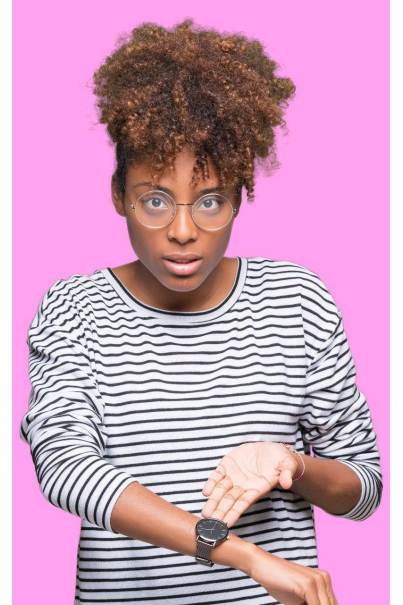
Developmental Services = Home and Community-Based Services

Background Information

The final Rule is not perfect. The government heard from many 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 government in charge of the rules is called CMS or Center for Medicaid and Medicare Services.



The Autistic Self Advocacy Network made a booklet called:

This Rule Rules!: The HCBS Settings Rule and You

It describes how the Home and Community-Based Services Settings Rule helps people with disabilities live in the community.

GMSA used information from this booklet to answer 3 questions:

1. What does the HCBS Settings Rule say?
2. What rights does the HCBS Settings Rule give me?
3. What rules do agencies have to follow?



Green Mountain Self-Advocates Adapted (with permission) information from **This Rule Rules** for these slides.

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 agencies follow rules in order to get money.



If an agency does not follow these rules, they will lose the money they get from the government to provide services.

What rights does the HCBS rule give us?

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.



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

If you live in a home controlled by an agency or with a shared living provider. There are rules:

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



Tenant Rights



Housing and Tenants' 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 homes controlled by agencies or shared living providers, you are like a tenant. You get all the same rights as any other tenant. Your agency or shared living provider is like your landlord. **They can't do unfair things to you.**

Choosing Where To Live

The Rule says that you need to have choices about where to live. Sometimes people make places to live that they say are “just for us.” This means that only people with disabilities can live there.

An example of a place where only people with disabilities live is a group home. Some people like living in group homes. Other people want to live in places that are for everyone, not just people with disabilities. The HCBS Rule says you should always have a choice about where to live. You can choose to live with other disabled people if you want. But, you have a right to choose to live somewhere that is for everyone. You have a right to live in the same places as people without disabilities.



More Privacy Rights

Agency staff and shared living providers have to do more to show they respect our privacy.

For example:

- 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 an agency controlled 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.

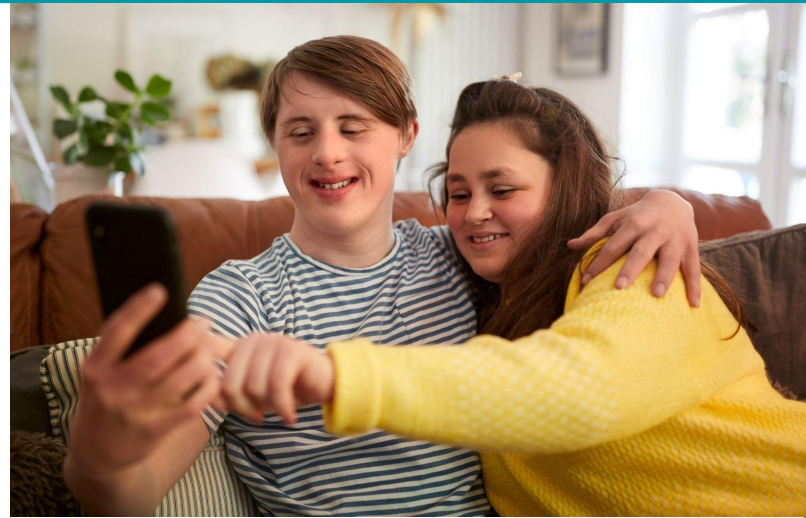
Visitors At Any Time

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 with visitors 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.



Access to Food at Any Time

Person-Centered Plans

You have a lot of choices about your services and supports. You can make these

choices by using a person-centered plan that

explains what kind of services you get. The HCBS Rule says you have a

right to a person-centered plan.



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

The state has to make sure agencies follow the HCBS Rule. Now Vermont already has rules for the agencies. That means the states has to change their rules. They have to follow the HCBS rules.



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.

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

The HCBS Rule helps people with high support needs.

Some people say that people who need a lot of support can't live in the community. They say the HCBS Rule will not work for people with high support needs.

This is not true! Some GMSA leaders have high support needs and they graduated from college!

People with high support needs can live in the community. They just need the right supports.



Our rights don't go away.

Heightened Scrutiny

There are some places that can't follow the HCBS Rule. For example institutions and hospitals can never follow the 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**.

Heartbeat Vermont is a place under heightened scrutiny.



Can my rights from the HCBS Rule get taken away?

Sometimes, those rights can get taken away, but it is very hard. They can't take away your main rights, like your freedom or privacy. They can't take away your right to live in the community.

Some people need help being safe, but getting the right kind of help breaks a part of the Rule. That's the only time the provider can break the Rule. Providers can only break the Rule if they tried other ways to help already. They can only break the Rule if no other kind of help works for you. Breaking the Rule can't be the first thing a provider tries.

If your provider has to break the Rule, they can only break it for you.

For example, let's say you live in a group home. Your provider still has to follow all of the parts of the Rule for everyone else.

Remember, everyone getting HCBS gets a person-centered plan. The person-centered plan says what kinds of help you get. If a provider needs to break the Rule to help you, the plan needs to be changed. You need to have a meeting to get your plan changed.

At this meeting, your providers have to:

- **Write down why they want to break the HCBS Rule.**
- **Talk to you about why breaking the Rule will help you.**
- **Tell you about the other ways they tried to help you.**

You have to agree that breaking the Rule is the right way to help you. Once you agree, it gets put in your person-centered plan. Here is an example of a time a provider might break the HCBS Rule: Miguel has a disability. He lives in a group home. Miguel's disability makes him always hungry, no matter how much he eats. It would be bad if Miguel ate food whenever he is hungry. He would never be able to stop eating. He might get sick.

The HCBS Rule says people must be able to eat whenever they want. This part of the HCBS Rule does not work for Miguel. At first Miguel tries to do other things. He makes his own rules to figure out when to eat. Unfortunately, those rules don't work for him. Miguel decides he needs help to stop eating so much. He calls his person-centered planning team together. Miguel and his case managers come up with a way to help. Now, Miguel will only get to eat at certain times. The rest of the time, his provider can tell him that he can't eat. That breaks the HCBS Rule. But it helps Miguel get what he needs. The rule for Miguel gets put into his person-centered plan. Miguel is happy the problem was fixed.