



*Easy Read Edition*

# **This Rule Rules!**

## **The HCBS Settings Rule and You**

**Part 4: What does the  
HCBS Rule do?**



**NASDDDS**

## 4. What does the HCBS Rule do?

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The **HCBS Rule** does a lot of different things. There are 2 main things it does:



It gives people important rights.



It makes **providers** follow rules 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.



That means **institutions** can't get money for HCBS.



It also means providers have to protect our rights.

# 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.



- Have a **person-centered plan**.



- Have freedom.



- Have respect and privacy.



- Not get **restrained** or **secluded**.

# Community Living



The Rule says that HCBS have to happen in the community.



That means you have the right to **community living**.

You have the right to:



- live in the community



- go into the community



- get the same kinds of jobs as people without disabilities



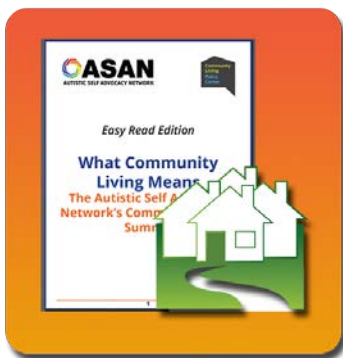
- decide how to spend your money



- choose how you spend your free time



- get health care in the community



You can learn more by reading ASAN's [Community Living Toolkits](#).



You have the right to live in your community just like everyone else.



The Rule says we get to live just like people without disabilities.



For example, people without disabilities can choose to go out whenever they want.



You have the right to go out whenever you want.



Providers can't control when you can go out.





They can't decide that you can only go out at certain times.



If they do, then that provider is not giving you HCBS.

## Choosing Where to Live



The HCBS Rule gives you the right to choose where you live.



The Rule says that you need to have choices about where to live.



You can't only be given one choice.



You can't get forced to have a roommate or live in a group home.



Sometimes people make places that they say are "just for us." Only people with disabilities can live there.



An example of this is a group home.



Some people like living in places like this.



But the Rule says you should always have a choice.

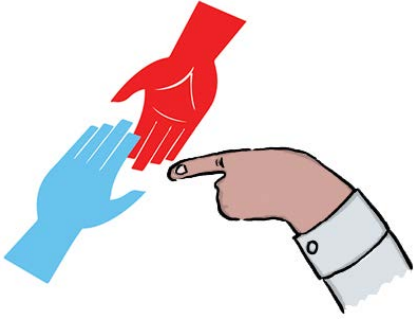


You have a right to choose to live somewhere that is for everyone.



You have a right to live in the same places as people without disabilities.

## Choosing Where to Get Services



You have the right to choose where you get services.



A lot of services happen in our homes.



We may need help getting dressed or taking a bath.



Those things usually happen where we live.



But, you can also choose to get HCBS outside your home.



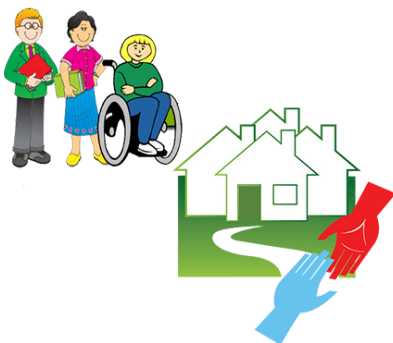
For example, some people might choose to have a helper come to their house.



But others might choose to meet their helper at the grocery store.



You get to choose which way works best for you.



You can also choose to get HCBS somewhere that is for everyone.



You don't have to get HCBS in places that are just for people with disabilities.



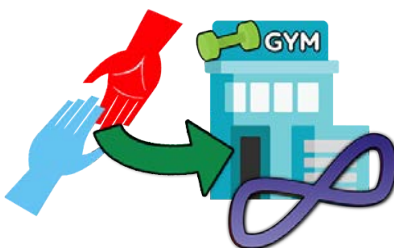
For example: Noah likes to work out. His provider has a gym just for people with disabilities.



Noah decides he doesn't like that gym. He wants to go to a different gym.



He wants to go to a gym that is for everyone.



Noah's provider needs to help him go to the gym he wants.



You can also choose which provider gives you services during the day.



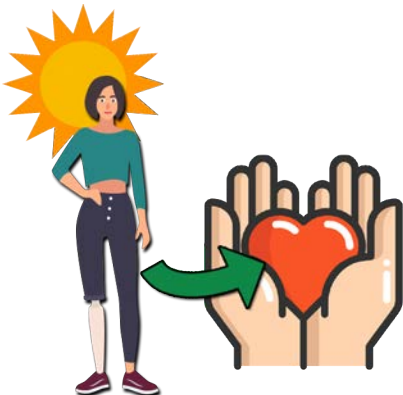
Some providers only give services to groups of people with disabilities.



You have the right to choose a different provider.



You have the right to choose a provider who will help you do what you want.



For example: Jin goes to a provider during the day.



The provider has a job program just for people with disabilities.



Jin wants to work in the community.



Jin decides to change providers.



Jin chooses a new provider that helps her work at the grocery store.



## Person-Centered Plans



You have a lot of choices about your services.



You can make these choices by using a **person-centered plan**.



This is a paper that says what kind of services you get.



The HCBS Rule says you have a right to get a person-centered plan.

1.=  
2.=

The Rule says a person-centered plan has to follow some rules.

The most important rules are:



- The plan is written in a meeting.



- You have to be at the meeting.



- You are in charge of the meeting.



- The meeting should have your providers, helpers, and anyone you want.



- The plan gets signed by everyone who works on the plan.



- The plan has to say who makes sure the plan is followed.



- The plan has to be checked every year in case it needs to be changed.



- If you want to change your plan, you can ask for a new meeting. You can change your plan whenever you want.



- The plan has to show that you live in the community.



- The plan has to show that you choose where you live.



- The plan has to show how your services help you meet your needs and goals.



You are in charge of making your person-centered plan!



The plan will only get made while you are there.



Everyone else helping you make the plan has to listen to you.



They have to help you get what you want and need.



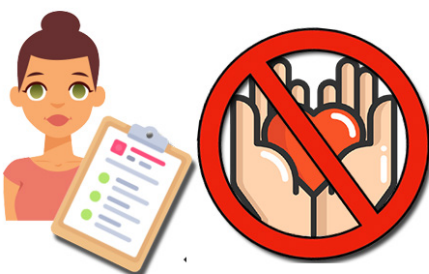
You get to choose who will be at the meeting.



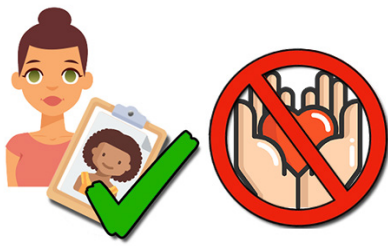
You have a right to a **case manager**.



A case manager helps make sure your plan works for you.



Your case manager can't be one of your providers.



Their job is to make sure your plan works for you, not for your provider.



You have the right to understand your person-centered plan.



You have the right to get help to understand.



You can get help reading the plan.



You can ask for information about the plan in easier language.



The Rule says your person-centered plan is very important.

# Freedom



You have the right to freedom.



Freedom means making your own choices about your life.

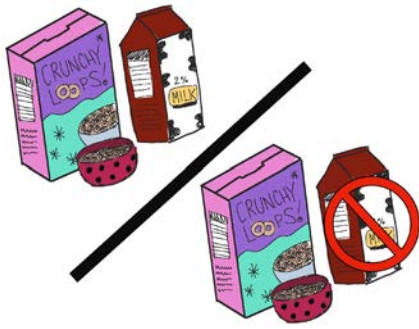


Real freedom means **real** choices.



This means small choices **and** big choices.





For example: You can choose to eat your cereal with milk or without milk.  
This is a small choice.



You can choose to move to another city, or stay where you are.  
This is a big choice.



Freedom means you get to choose where to go and how to spend the day.



You get to choose who your friends are and who you talk to.



The HCBS Rule says providers can't make you go out or stay inside.



They can't stop you from talking to anyone.



The HCBS Rule says that providers have to let you make all kinds of choices.



For example: Brian gets to choose if he wears a red or blue shirt.



But he doesn't get to go out to eat when he wants to.



He doesn't get to make big choices.



Brian does not have freedom.



Brian is not getting HCBS.



HCBS should never take away your freedom.



The HCBS Rule says you ***always*** have the right to make choices.

## Respect and Privacy



The HCBS Rule gives you the right to respect and privacy.

Sometimes, providers try to take away our privacy.



- They come into our rooms without asking.



- They spy on us when we want to talk in private.

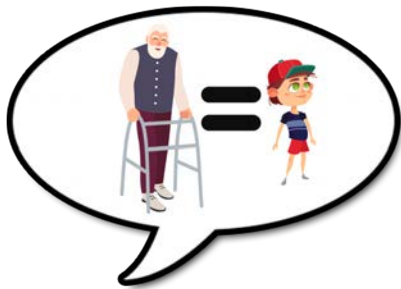


- They do not leave when we tell them to.



- They ask us embarrassing questions about our lives.

Sometimes, providers don't respect us.



- They treat us like children instead of adults.



- They “help” us when we don't want help.



- They say rude or mean things to us.



- They make fun of us.



- They hurt us.



- They don't listen to us.



The HCBS Rule says these things should not happen to us.



We deserve the same respect and privacy as everyone else.

## No Restraint and Seclusion



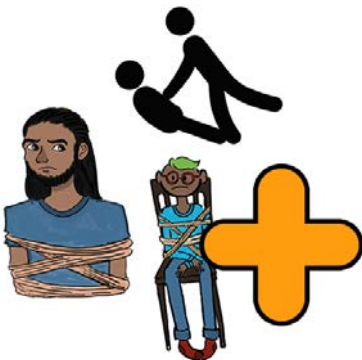
**Restraint** is when someone stops someone else from moving.



This can mean someone holding another person down.



It can mean tying a person down to a chair.



There are other kinds of restraints too.



Restraints are dangerous.



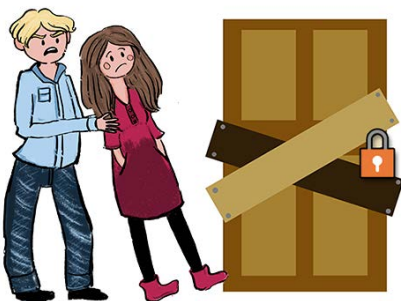
Some people have even died because they were restrained!



**Seclusion** is when someone locks someone else in an empty room.

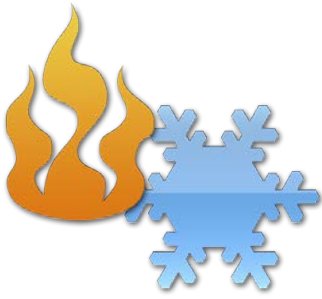


Seclusion is dangerous, too.



Sometimes, the person will get pushed or pulled into the room. They may get hurt.





Sometimes the room is too hot or too cold.



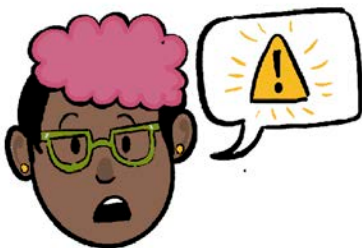
Sometimes the person will get left there a very long time.



They may get hungry or thirsty. They may need to use the bathroom.



Restraint and seclusion are scary.



People can feel scared even after it ends.



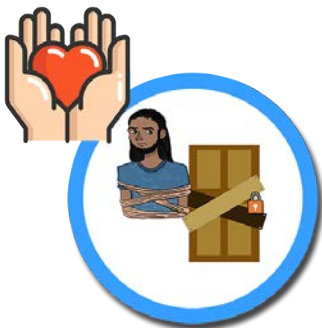
They might need a lot of help to feel safe again.



The HCBS Rule says that no one should ever be restrained.



The HCBS Rule says that no one should ever be secluded.



Some providers use restraint and seclusion on people with disabilities.

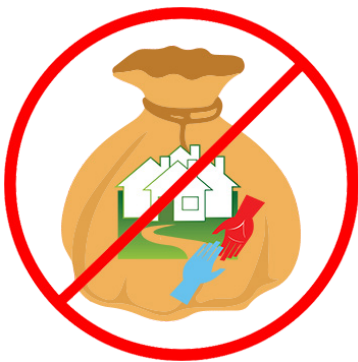


The HCBS Rule says they can't do that anymore.

## Are there special rules for some HCBS providers?



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, your HCBS provider owns the group home.



This is called a **provider-owned setting**.



CMS looked at provider-owned settings when they made the HCBS Rule.



CMS found out that provider-owned settings usually tried to control us a lot.



When we lived in provider-owned settings, we spent less time in the community.



It was easy for provider-owned settings to turn into institutions.



CMS thought that was a problem.



CMS wrote the HCBS Rule to solve this problem.



Some parts of the HCBS Rule are only for provider-owned settings.



These parts make sure that provider-owned settings are actually HCBS.

The parts of the Rule for provider-owned settings are about:



- Tenant rights



- Extra privacy rights



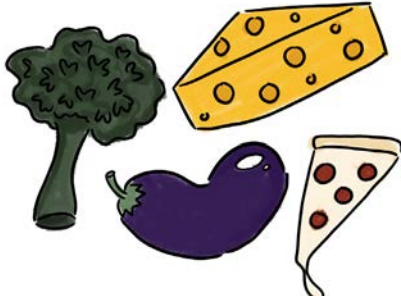
- Physical accessibility



- 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.

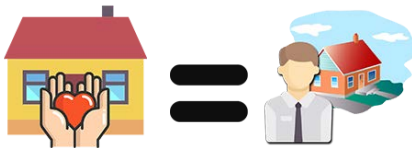




The HCBS Rule says that in provider-owned settings, you are like a tenant.



You get all the same rights as any other tenant.



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 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 keys to your room or house.



- If you have a roommate, you get to pick your roommate.

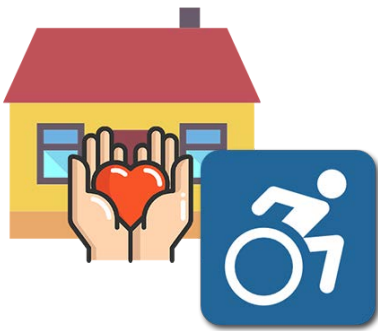


- You can decorate your room or house any way you want.

## Physical Accessibility



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



If you work in a provider-owned setting, it has to be accessible.



It does not matter what kind of disability you have.



Providers have to make sure your house works well for you.

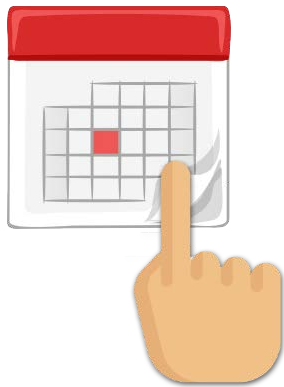
# Right to Control Your Daily Life



You have the right to do what you want to do every day.



You get to decide how to spend your time.



You get to decide when to do things.



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 go somewhere you don't want to go.



They can't force you to do something you don't want to do.

## Visitors At Any Time



You can always have visitors.



You can have visitors whenever you want.



You can have visits from anyone you want.



That means your friends, family, partners, or anyone else you want.



HCBS providers can't control what you do together while they are there.



You can have people sleep over if you want.



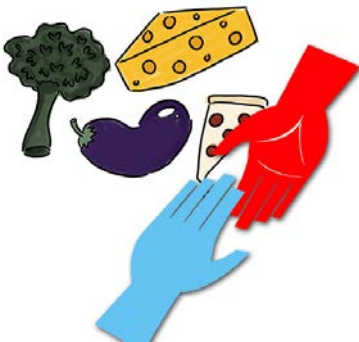
## Access to Food at Any Time



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.



They can't make you only eat at certain times.

# What are the facts about the Rule?



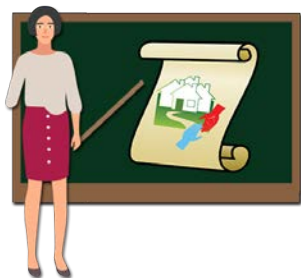
Some people have ideas about the HCBS Rule that are wrong.



These ideas make it harder for states to follow the HCBS Rule.



They make things harder for people who want our rights.



Here are some facts about the HCBS Rule.



You can tell people the truth about the HCBS Rule.

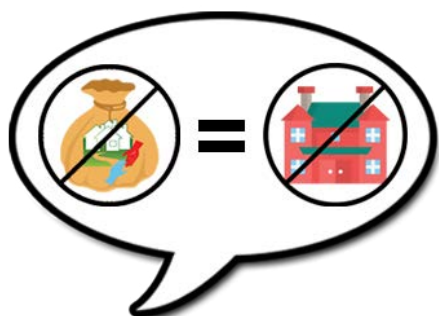
## #1: The HCBS Rule doesn't take away "choice."



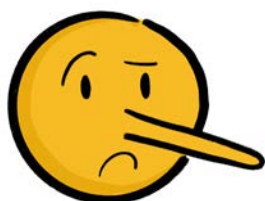
The HCBS Rule says institutions can't get HCBS money.



Some people think that gives us less "choice" about where to live.



They say that without HCBS money, people with disabilities can't live in institutions.



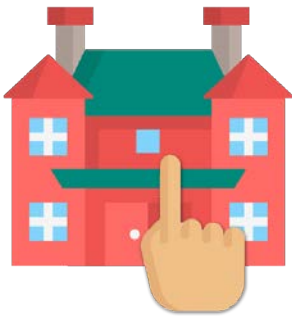
**This is not true!**



Institutions get their own money from Medicaid.



That money doesn't get taken away because of the HCBS Rule.



People with disabilities can still live in institutions if we want to.



Institutions just can't get money that is for HCBS.

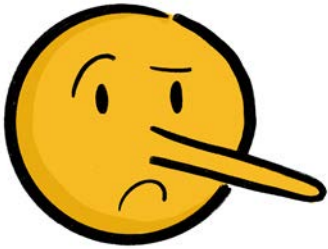
## #2: The HCBS Rule helps people with high support needs.



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.



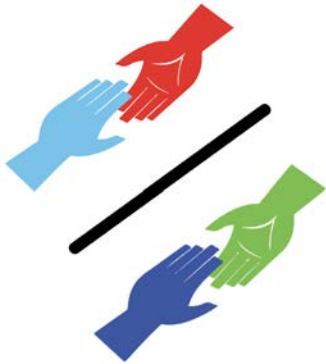
**This is not true!**



People with high support needs can live in the community.



They just need the right supports.



The HCBS Rule gives different supports to each person.



The supports get put in their person-centered plan.



That makes sure everyone's needs get met.



The HCBS Rule is about our rights.



Rights are big ideas about how we live our lives.



Rights are things that every person wants and needs.



It doesn't matter what kind of disability we have.



It doesn't matter what kind of support needs we have.





We all deserve these rights.



The HCBS Rule helps us get these rights.

### #3: The HCBS Rule doesn't close institutions.



The HCBS Rule does not say that institutions have to close.



It just says that institutions can't get money meant for HCBS.



An institution can get other kinds of government money to stay open.

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



States have to make sure providers follow the HCBS Rule.



That means states have to change their own rules, too.



States have to make a plan for how they will follow the HCBS Rule.



This is called an **HCBS transition plan**.



States have to give this plan to CMS.

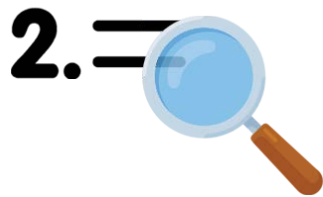


CMS has to say okay before the state can use it.

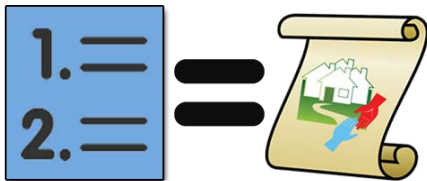
# HCBS Transition Plans

The HCBS transition plan has to have these things in it:

1.=



- The state has to look at all of the rules it already has.



- They figure out which ones already follow the HCBS Rule.



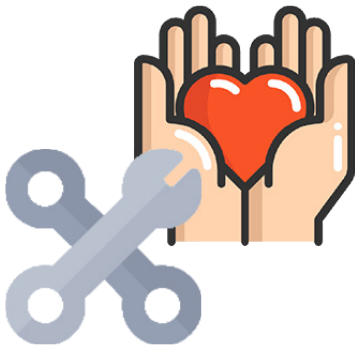
- They figure out which ones don't follow the HCBS Rule.



- They make a plan to fix the ones that don't follow the Rule.



- The state figures how to tell if a provider is following the HCBS Rule.



- They figure out how to fix providers that don't follow the Rule.

1... 2...  
3... 4...

Making HCBS transition plans take a lot of steps.



First, the state has to let people know they are making an HCBS transition plan.



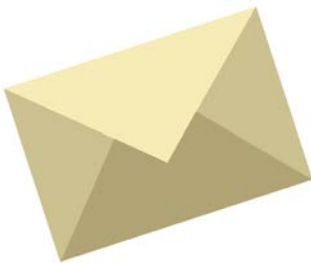
People can send their state what they think should be in the plan.



Then, the state put those ideas into their transition plan.



Next, the state gives CMS their first draft of the transition plan.



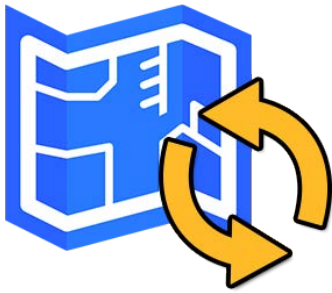
CMS sends the state a letter.



The letter says what CMS wants the state to change in the next draft.



CMS needs to make sure states explain how they will follow all the rules.



After that, the state makes the changes that CMS asks for.



They also show the first draft to people in their state.



They get ideas from people like you and me. They put our ideas into the second draft.





Then, the state sends CMS the second draft.



CMS looks at the state's new draft.



They decide whether the draft is okay or not.



If it is not okay, they send it back to the state.



The state keeps making new drafts until it looks good.

The final draft usually has these things in it:



- A plan to make sure providers keep following the HCBS rule.



- A plan to find out which providers don't follow the HCBS rule.



- A plan for what to do if a provider doesn't follow the HCBS rule.



- A way to figure out which providers ***can't*** follow the HCBS Rule.



For example, some institutions get HCBS money right now.



They can never follow all the parts of the HCBS rule.



The state needs to make sure they stop getting HCBS money.



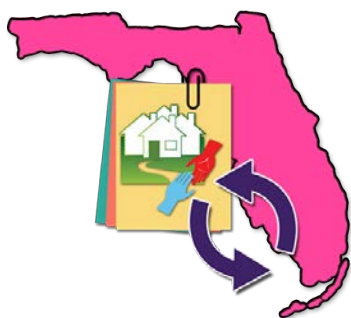
- Some people who are supposed to get HCBS are still in institutions. States need to figure out how to get these people real HCBS.



Finally, CMS decides that the plan looks good.



Now, the transition plan is done!



States need to make sure they follow the plan.



They need to make sure everyone follows the HCBS Rule.



Transition plans can take a long time to make.



Right now, only 13 states finished their plan.



We still have a long way to go to follow the HCBS Rule.



Even when all of the transition plans are done, states have more to do.



They have to make sure everyone keeps following the HCBS Rule.



They will have to do this forever.

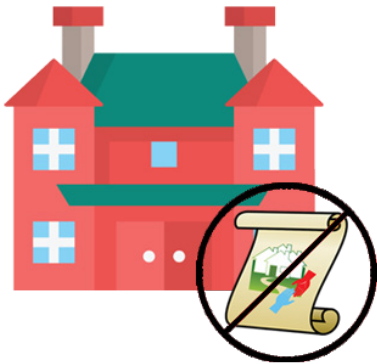


Our rights don't go away.

## 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.



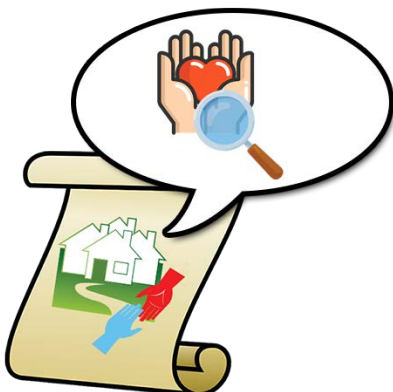
But some of these places look like institutions.



States need to make sure these places aren't institutions.



They do that by giving these places **heightened scrutiny**.



The HCBS Rule says which places get heightened scrutiny.



Some places that get heightened scrutiny are:



- Places that used to be institutions.



- Places in the same building where an institution is.



- Places that are next to an institution.



- Places far away from the community.



- Places where only disabled people live.



States take a closer look at these places.



They go visit these places.



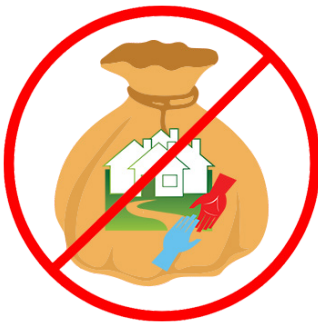
They talk to people living there.



They decide whether or not these places follow the HCBS Rule.



They can decide a place doesn't follow the HCBS Rule.



Then, that place won't get HCBS money.



Or, they can decide a place does follow the HCBS Rule.



Then, that place can get HCBS money.



States write down what they decide in their HCBS transition plan.



Then, CMS decides if they agree with the states.

## Why does the HCBS Rule matter to me?



The HCBS Rule gives you rights!



These rights mean you are in charge of your services.



These rights mean your provider has to treat you fairly.



These rights make it easier to get your services in the community.



Medicaid only has some money to spend on HCBS.



We want that money to go to services in the community.



We don't want that money to go to institutions.



The HCBS Rule makes sure that money goes to services in the community.



When services in the community get more money, they work better.



More money can also help people get more services in the community.



**We all deserve good services that help us live good lives.**

# Words to Know





## case manager

Someone who helps make sure your person-centered plan works for you.



## community living

Living in the same places as people without disabilities.



## Centers for Medicare & Medicaid Services (CMS)

The government office that runs Medicaid.



## home and community-based services (HCBS)

When people get LTSS in their community.



## HCBS Rule

A rule that CMS made. It helps disabled people get the services we want in our communities. It makes sure institutions can't get HCBS money.



## HCBS transition plan

A plan states make that says how they will follow the HCBS Rule.



## heightened scrutiny

When states look closely at certain places to make sure they aren't institutions.



## institutions

Places where a lot of people with disabilities live. People living in institutions usually did not decide to live there. They were usually put there by someone else.



## landlords

People who own houses and rent them to someone else.



## Medicaid

A program the government made to help people with disabilities. Medicaid gives people health care.



## person-centered plan

A paper that says what kind of services you get.



## providers

People or places that give health care. Some types of providers are doctors or hospitals.



## provider-owned setting

What a place is called when an HCBS provider owns the place where you get HCBS.



## restraint

When someone stops someone else from moving.



## seclusion

When someone locks someone else in an empty room.



# tenants

People who rent houses.

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