



ASAN

AUTISTIC SELF ADVOCACY NETWORK

Settings

Rules Resources

**How can I find out what
rights I have under the
HCBS Rule?**



What is the HCBS Rule?

This guide will talk about parts of Medicaid's Home and Community-Based Services (HCBS) Final Rule. This guide will call it the "HCBS Rule" for short.

The HCBS Rule is a rule the government made. The HCBS Rule says people with disabilities have rights when we get disability services in our communities. The HCBS Rule talks about these rights. The HCBS Rule talks about what people who give us services have to do to respect our rights.

You can learn more about the HCBS Rule in our toolkit, [This Rule Rules!](#)

What is community living? What is an institution?

People with disabilities want to live in the community with everyone else. We don't want to live in separate places just for us. **Community living** means living in the same places as people without disabilities. A community can be a neighborhood, town, or city. It can be any place where people with and without disabilities live together. Community living means getting to make our own choices about our lives.

We can choose things like:

- Where we go to work or school
- How we spend our free time
- What we want to eat
- How we decorate our room
- Who we make friends with
- Who helps take care of us if we need help

Some disabled people don't live in their communities. They live in institutions instead. **Institutions** are places where a lot of disabled people live. People in institutions usually did not decide to live there. They were put there by someone else.

Institutions are not run by the people living there. Institutions are run by the people who work there. People living in institutions usually can't leave when they want to. They usually can't spend their free time how they want to. Other people get to make choices about how they live their lives. **Institutions are bad for everyone.**

Nobody wants or needs to live in an institution! When someone has to live in an institution, it is much harder to use their rights. When someone lives in their community, it is much easier to use their rights.

People on HCBS waivers should not be in institutions

Some people with disabilities get **long-term services and supports (LTSS)**. LTSS are services that help disabled people live our everyday lives. Some examples of LTSS are:

- Job coaches
- Transportation
- An in-home helper

There are different kinds of LTSS providers. **Providers** are people or groups who give people with disabilities LTSS.

Some people get LTSS in institutions. Other people get LTSS in their community. When people get LTSS in their community, it is called **home and community-based services (HCBS)**.

Medicaid is the program that pays for LTSS in institutions and HCBS. Medicaid is a health care program. The government pays for Medicaid.

Medicaid has an **institutional bias**. "Institutional bias" means that Medicaid will automatically pay for LTSS in institutions. That means people in institutions can get LTSS right away. But Medicaid won't automatically pay for HCBS in the community.

Medicaid says people need a **HCBS waiver** to pay for HCBS. An HCBS waiver is a document. An HCBS waiver says you can get LTSS from places besides in an institution. It says you want to get HCBS instead. And it says Medicaid will pay for the HCBS.

If people don't have an HCBS waiver, Medicaid won't pay for HCBS. That means people who want HCBS may have to wait a long time to get HCBS. They may have to wait years and years.

If you have an HCBS waiver, you should not be in an institution! The HCBS Rule says that if you have an HCBS waiver, you should be living in the community. The **HCBS Rule** is a rule the government made. The HCBS Rule says what kinds of LTSS **are** HCBS. The HCBS says what kinds of LTSS **are not** HCBS. The HCBS Rule says people with disabilities have rights when we get HCBS. The HCBS Rule talks about these rights. The HCBS Rule talks about what providers have to do to respect our rights.

The HCBS Rule gives us these rights

The HCBS Rule gives us lots of 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.
- We will talk about each of these rights.

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 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. (**Providers** are the people who give you HCBS.) 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. Some examples of these places are:

- A group home
- An assisted living facility
- A foster home for adults with disabilities
- An apartment building that only rents apartments to people with disabilities

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.

For example: Kyle is choosing where to live. Kyle's provider offers him a choice. Kyle could live in a group home. Or Kyle could live in his own apartment with a friend. Kyle gets to choose where he wants to live.

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 disabled people. 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.

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.

For example: Lina is getting HCBS. She gets a person-centered plan. Lina meets with her providers, helpers, family, and case manager. They help Lina write her person-centered plan. The plan says what services Lina will get. The plan says where Lina will live. The plan says that Lina will live in the community. The plan says how Lina's services will meet her needs and goals.

You have the right to a person-centered plan already. You don't have to wait for the HCBS Rule to start working to get this right. You can ask to get a copy of your person-centered plan if you don't already have a copy. Talk to your case manager. Your case manager can get you a copy of your person-centered plan. If you don't

know who your case manager is, talk to your provider. Your provider should know who your case manager is.

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.

Here is another example: Karla lives in a group home. Karla gets to make small choices. She gets to choose whether she goes to the park or to the movies on Saturdays. Karla also gets to make big choices. She gets to choose whether she stays in the group home or moves into her sister's house. Karla has freedom. Karla is getting HCBS.

HCBS should never take away your freedom. The HCBS Rule says you always have the right to make choices.

For example: Sean lives in a group home. The group home provider takes away Sean's freedom to punish Sean. When Sean doesn't do his laundry, the provider won't let him go outside. Sean only gets to go outside if he does all his chores. Sean is not getting HCBS. Sean does not have freedom.

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.

For example: Rianne gets HCBS. She has an in-home helper. Rianne's in-home helper takes away Rianne's privacy. The in-home helper follows Rianne around even when Rianne wants to be left alone. The in-home helper asks Rianne embarrassing questions about her life. Rianne's in-home helper does not respect Rianne. The in-home helper makes mean jokes about Rianne. The in-home helper doesn't listen when Rianne tells them to stop. All of these things are wrong! Rianne's in-home helper shouldn't do these things. Rianne's in-home helper should respect Rianne. They should respect Rianne's privacy.

Here is another example: D'Shaun gets HCBS. D'Shaun lives in a group home. The staff at D'Shaun's group home make a rule. The rule says that the people living in the group home have to have their bedroom doors open all the time. This takes away D'Shaun's privacy. He should be able to close his bedroom

door when he wants. The group home staff shouldn't be able to come into D'Shaun's bedroom whenever they want.

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.

Sometimes, people are given medicine to slow them down. The medications don't have any other purpose. The medications are only to slow people down and make them easier to control. This is called **medical restraint**. Medical restraint is also called chemical restraint. Medical restraint is a form of restraint.

For example: Juliana receives HCBS. Juliana lives in a group home. Juliana's disability makes her move around a lot. Juliana isn't hurting anyone when she moves around. But the staff at her group home don't like that she moves around a lot. So the staff give Juliana medication to make her stop moving as much. The medication has bad side effects. It makes Juliana really tired all the time. It makes her feel trapped. This is medical restraint.

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, including medical restraint. 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.

For example: Hanna's group home used to use seclusion. They used to lock people in rooms and leave them there for a long time. Being secluded

scared Hanna. Hanna also got scared seeing her housemates secluded. Now, because of the Settings Rule, the group home doesn't use seclusion anymore. This makes Hanna happy. She doesn't have to be scared about being secluded 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 is the part of the government that made the HCBS Rule. 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.

When you live in a provider-owned setting, you are like a tenant. You get all the same rights as any other tenant. This does not just mean you have the same rights as any other person in the provider-owned setting. It means you have the same rights as any other tenant in any home or apartment in your city. This includes tenants who do not live in disability-specific places.

For example: Joao lives in a group home. Joao is a tenant in the group home. The group home provider is like Joao's landlord. Joao has all the same rights as any other tenant in his city. Joao's city has a law that says all tenants have the right to heating during the winter. The law says landlords have to make sure all tenants have heating during the winter. Joao has this right, too. His group home has to make sure he has heating during the winter.

The HCBS Rule says you get to have a lease. A **lease** is a legal document. It says what your rights are when you rent a house or apartment. It says what your responsibilities are when you rent a house or apartment. It says what your landlord's rights are when they rent you a house or apartment. It says what your landlord's responsibilities are when they rent you a house or apartment.

When you have a lease, it is harder for your provider or landlord to change the rules about where you live. A lease also should make it harder for your provider or landlord to make you leave where you live unless they have a very good reason.

For example: Daisy lives in a group home. Daisy's group home is a provider-owned setting. When Daisy moved into the group home, she signed a lease. The lease says what Daisy's rights are when she lives in the group home. An example of Daisy's rights is that the staff of the group home give Daisy privacy in her room. The lease says what Daisy's responsibilities are when she lives in the group home. An example of Daisy's responsibilities is that she needs to throw out her trash.

Sometimes, if you live in a provider-owned setting, the legal document you get will not be called a lease. It might be called something else. But the legal document must have all the same parts as a lease. It needs to talk about your rights in the provider-owned setting. It needs to talk about your responsibilities in the provider-

owned setting. The legal document needs to give you all the same rights as a lease would.

The legal document can't make it easier for a provider to make you leave where you live than a lease would. The legal document can't make it easier for a provider to change the rules about where you live than a lease would.

For example: Mike moves into a group home. Mike's group home is a provider-owned setting. When Mike moves in, he gets a legal document that talks about his rights and responsibilities in the group home. This legal document isn't called a lease. It's called a "living agreement" instead. But the legal document has all the same parts as a lease. It still has the same legal power as a lease. It gives Mike all the same rights as a lease would.

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.

For example: Hamid lives in an apartment his provider owns. Hamid's apartment is an example of a provider-owned setting. Hamid and his in-home helpers are the only ones who have a key to his apartment. Hamid can lock his apartment's front door whenever he wants. He doesn't have to ask anyone for permission to lock his front door. Hamid can decorate his apartment any way he wants. So he decides to put up sports posters all over his apartment. This is Hamid's choice. His provider has to let him decorate his apartment any way he wants.

Physical Accessibility

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

For example: Roberto lives in a group home. The group home is an example of a provider-owned setting. Roberto uses a wheelchair. His provider needs to make sure that the group home is accessible to Roberto. They need to make sure that there are ramps as well as stairs. They need to make sure that all the doors are wide enough for Roberto to get in and out. They need to make sure that places like the bathroom or kitchen are accessible to Roberto.

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.

For example: Lisa lives in a group home. Lisa's group home is an example of a provider-owned setting. Lisa gets to decide what she wants to do every day. She gets to make her own schedule. Lisa's housemates decide to go bowling. But Lisa doesn't want to go bowling. So she stays home. Lisa decides she wants to go to the mall. Even if her housemates don't want to go to the mall, she still gets to go to the mall. The provider that runs the group home can't force Lisa to go bowling with her housemates. And the provider has to let Lisa go to the mall, even if her housemates don't want to.

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.

For example: Farzad lives in a group home. Farzad's group home is an example of a provider-owned setting. Farzad wants to have their boyfriend visit them and sleep over. The group home staff has to let Farzad have their boyfriend over. The group home staff can't make rules about what Farzad and their boyfriend do together. The group home staff can't say that Farzad must leave their bedroom door open while their boyfriend is visiting.

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.

For example: Lorraine lives in an apartment building just for people with disabilities. Lorraine's provider owns the apartment building. This is an example of a provider-owned setting. Lorraine has a staff member in her apartment 24 hours a day. The staff member can't stop Lorraine from making food when she wants. The staff member needs to help Lorraine make food when she wants.

Here is another example: Grace lives in an assisted living facility. The assisted living facility has a central kitchen that all the people living there can use. The kitchen is only open during certain times. But Grace can still have snacks when the kitchen is not open. Grace can still keep snacks in her room. She has a mini-fridge and a microwave in her room. Grace can still make some meals when the kitchen is closed.

Some of these rights you will get right away once the Settings Rule starts working. Some of these rights will take longer. We will talk about why this is in the next two sections.

Some of these rights we get right away

The HCBS Rule starts working on March 17, 2023. When the HCBS Rule starts working, you will get some of your rights right away. These rights are:

In all places you receive HCBS

- Privacy and respect
- Freedom from restraint and seclusion
- Having control of your own belongings

In provider-owned settings

- A lease or similar legal document
- Privacy in your house, apartment, or room
- A door that locks
- Freedom to decorate your house, apartment, or room however you want
- Getting food at any time
- Having visitors at any time
- Physical accessibility

You will get these rights right away no matter what state you live in.

Some will take longer.

Some of our rights might take longer. These rights can include:

- Living in the community with people without disabilities
- Getting a job
- Having a private house, apartment, or room all to yourself
- Getting to choose your roommate, if you have one
- Living in a non-disability specific setting

We will go over each of these rights. Then we will explain why these rights might take longer.

Living in the community with people without disabilities

Right now, some people with disabilities live in places that are separate from the bigger community. This might look like a group home in an area where not many people live. The group home was specifically built there to separate people with disabilities from the community. Or, it might look like a provider-owned apartment in a big city. But the staff at the apartment don't let the people with disabilities living there go out into the community. The staff say the people with disabilities can only do activities in the apartment.

The HCBS Rule says that you have the right to live in the community with people without disabilities. This means you have the right to:

- Live with people without disabilities.
- Go out into the community to do activities with people without disabilities.
- Get a job in the community with people without disabilities. (We will talk about this right more in the next section.)

Here is an example of someone who is living in the community with people without disabilities: Lonnie is autistic and has Down Syndrome. Lonnie lives in an apartment with two friends. Neither of his friends has a disability. Lonnie can leave his apartment at any time. He can go out to do things in the community, like going to the movies, whenever he wants. Lonnie has a job in the community. He works at a local coffee shop. Lonnie's coworkers are mostly people without disabilities. Lonnie is living in the community.

Here is an example of someone who is not living in the community with people without disabilities: Jordan is autistic and has cerebral palsy. They live in a group home. The group home is way out in the countryside. It is not near any big cities. Very few people without disabilities live near the group home. There are very few things to do near the group home. The only other people Jordan regularly sees are other people with disabilities and staff members. If Jordan wants to leave the group home, they have to travel with a group home staff member.

Jordan is not living in the community.

Here is another example of someone who is not living in the community with people without disabilities: Mack is autistic and has an intellectual disability. Mack lives in a group home in a big city. All of Mack's neighbors are people without disabilities. But Mack and the other people living in the group home rarely ever leave the group home. When they do, they only go to events for people with disabilities. Mack and the other people living in the group home have jobs. But their jobs are in a workshop where only people with disabilities work. People without disabilities come into the group home to do activities with the people living there. But Mack and the other people living in the group home don't get to go out into the community. Even though the group home is in a big city, Mack is not living in the community.

Getting a job

The HCBS Rule gives you the right to get a job in the community if you want to. You don't have to get a job in a place that's just for people with disabilities. (Places that only hire people with disabilities are sometimes called "sheltered workshops" or "segregated employment." When you have a job in the community with people without disabilities, it is called "integrated employment" or "competitive integrated employment." You can learn more about different types of employment in our toolkit "[Real Work For Real Pay: A Self-Advocate's Guide to Employment Policy.](#)")

If you want a job in the community, your provider has to help you get one. They have to help you in ways like:

- Helping you find jobs you want to work at.
- Helping you apply for jobs you want to work at.
- Giving you supports at work if you need them (for example, having a job coach at work).
- Telling you how having a job might affect your benefits (like Medicaid or SSI/SSDI).
- Helping you change jobs if you want to.

Here is an example of someone getting a job in the community: Luka is working in a sheltered workshop. She only works with other people with disabilities. Luka wants to get a job in the community. So she talks to her provider. The provider has Luka visit different job sites. That way, Luka can learn about different jobs she might want. Luka decides she wants to work at an animal shelter. So Luka's provider helps her apply to jobs at local animal shelters. Luka's provider helps her find a job coach who can help her at work. Luka's provider talks with Luka about how having a job might affect her Medicaid benefits. If Luka wants to change jobs in the future, her provider can help her with that, too.

Having a private house, apartment, or room all to yourself

The HCBS Rule says that you have the right to have a private house, apartment, or room all to yourself if you want it. You don't have to have roommates unless you

want to. Your provider can't force you to have roommates.

For example: Maura lives in a group home. She has to share her bedroom with a roommate. Maura wants to move out of the group home. She wants to live in her apartment. Maura's provider needs to help her move out of the group home. They need to help her find an apartment she can live in.

Here is another example: Tyler lives in an apartment with two other people with disabilities. Each person in the apartment gets their own room. None of them have to share rooms.

Getting to choose your roommate, if you have one

The HCBS rule says that if you have a roommate, you get to pick your roommate. If you want to change your roommate, you can. Your provider has to tell you about the process for changing your roommate.

For example: Liam and Hassan are roommates. They do not like each other. Their provider reminds them of the process for choosing new roommates. Liam and Hassan choose new roommates. Now, they don't have to share a room anymore.

Living in a place that's not just for people with disabilities

The HCBS rule gives you the right to live in a home or apartment with people without disabilities. You don't have to live somewhere that is just for people with disabilities. You can choose where you want to live. You can choose who you want to live with. If you want to live in your own home or apartment, you can. If you want to live with friends, family members, or partners, you can. If you want to live with other people with disabilities, but not in a provider-owned setting, you can.

Why might I have to wait longer for these rights?

You may have to wait longer for these rights. It depends on what state you live in. This is because of COVID-19. COVID-19 is a bad disease that has spread around the world. It has caused a lot of problems all around the world. One problem is that a lot of people got sick and could not work. This included HCBS workers and staff.

This made it harder for some states to make sure that every provider could follow all of the HCBS Rule. For example, because of COVID-19, many providers don't have enough staff to provide services to all the people who need them. This makes it hard for the providers to follow all the parts of the HCBS Rule.

Because of this, some states have gotten exceptions to following the HCBS Rule right away. The exceptions say that providers don't have to follow all the parts of the HCBS Rule when the HCBS Rule starts in 2023. But states do have to tell CMS when providers will be able to follow all the parts of the HCBS Rule. States have to have a plan for how providers will be able to eventually follow all the parts of the HCBS Rule. These plans are called **Corrective Action Plans (CAPs)**.

When you get these rights depends on your state's CAP. States have to say in their CAPs when they will give you all your rights. CMS told states that states shouldn't take longer than 5 years to give you all your rights. It will probably take states between 1 to 2 years to give you all your rights. Check your state's CAP for the exact timeline.

Not every state has a CAP. We will talk more about CAPs and how to find if your state has one in the next section.

How do I know if my state has a CAP?

CAPs are for states that need more time before they can follow the HCBS Rule. States might need more time to make or follow their transition plan. A transition plan is a plan for how the state will follow the HCBS Rule. It has the following 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.
- Some people who are supposed to get HCBS are still in institutions. States need to figure out how to get these people real HCBS.

To find out if your state has a CAP, go to [CMS's page on state transition plans](#). Find your state in the column labeled "State" on the left. Then, look at the column labeled "HCBS Settings Corrective Action Plans" on the right. If there is a link that

says "[Your State's Name] Proposed CAP," it means your state has a CAP.

This might change in the future. Some states might realize they need more time to follow the rule. Some states that have CAPs might decide they don't need them any more. If you're not sure about your state's CAP, you can talk to one of the groups in the next section. They can help you find out about your state's CAP.

Who can help me understand my state's CAP?

There are several groups in your state that can help you understand your state's CAP.

Developmental Disability (DD) Councils

You can ask your state's developmental disability (DD) council for help understanding your state's CAP. **DD councils** work to help people with developmental disabilities. They figure out problems that the state can fix. Every DD council has to have people with developmental disabilities on it. That way, we can let our state know what problems we think are important. You can find your state's DD council's contact information here: <https://nacdd.org/councils/>

Protection and Advocacy Organizations (P&As)

You can ask your state's protection and advocacy organization (P&A) for help understanding your state's CAP. **P&As** help people with disabilities fight for our rights. P&As make sure states and other people or groups, like providers, follow disability laws. There is a P&A in every state. You can find your P&A by going to <https://www.ndrn.org/about/ndrn-memberagencies/>

Centers for Independent Living (CILs)

You can ask your local center for independent living (CIL) for help understanding your state's CAP. CILs are groups that work with people with disabilities. CILs help us get what we need to live in the community. There is usually more than one CIL in a state. You can find your local CIL by going to <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>.

How can I learn more about what rights I have?

Different groups are making resources about the HCBS Rule. Here are some resources you can use:

Resources from ASAN

ASAN has several resources about the HCBS Rule.

First, we have our toolkit [This Rule Rules!](#) This toolkit has plain language and Easy Read versions. This toolkit talks about the HCBS Rule. This toolkit talks about your rights once the HCBS Rule starts working.

Second, ASAN has [resources on improving HCBS](#). One of these resources is for [self-advocates and families](#). This resource is not written in plain language. This resource talks about what you can do to advocate for better HCBS. It talks about parts of the HCBS Rule and how the HCBS Rule will help make HCBS better.

Finally, ASAN has [recorded webinars about the HCBS Rule](#). These webinars are not in plain language. These webinars talk about things like:

- What the HCBS Rule actually says
- How the HCBS Rule will affect housing and living spaces for people with disabilities
- How you can get involved in making sure states follow the HCBS Rule
- How the HCBS Rule will affect jobs and day programs for people with disabilities
- How the government will make sure states and providers follow the HCBS Rule

Resources from the Council for Quality and Leadership (CQL)

The Council for Quality and Leadership (CQL) is a group that works to make sure

people with IDD have good lives. The CQL has some [videos about the HCBS Rule](#). The videos are mostly in plain language. The videos talk about things like:

- What HCBS are
- What the HCBS Rule says
- When and how providers can take away your rights
- What the HCBS Rule says about provider-owned settings
- What rights the HCBS Rule gives you

Boggs Center Resources

The Boggs Center is an organization that is part of Rutgers University. The Boggs Center works to make sure people with IDD can live good lives. The Boggs Center has two toolkits about the HCBS Rule. One toolkit is meant for people with disabilities. The other toolkit is meant for supporters of people with disabilities, like family members and support workers.

The toolkit for people with disabilities is called [Your Right to a Community Life](#). This toolkit is not written in plain language. This toolkit talks about your rights under the HCBS Rule. This toolkit asks you about your life right now. It asks you questions about whether you are living the life you want to live. It gives you suggestions about how you can advocate for yourself.

The toolkit for supporters is called [Supporting the Right to a Community Life](#). This toolkit talks about how supporters can help a person with a disability live their best life. It gives supporters questions to ask to find out about a person's life. It gives supporters tips about helping people advocate for their needs.

Who can I talk to if someone isn't respecting my rights?

If someone, like a provider, isn't respecting your rights under the HCBS Rule, you have options. You could talk to the provider that isn't respecting your rights. You could talk to someone at the agency or company the provider works for. You could tell your state government about it. We cover all these options and more in our fact sheet "Who can I talk to if someone isn't respecting my rights?"
