



ASAN

AUTISTIC SELF ADVOCACY NETWORK

This Rule Rules!

The HCBS Settings Rule and You

1. To Start

This toolkit is about Medicaid’s Home and Community-Based Services (HCBS) Final Rule. This toolkit will call it the “HCBS Rule” or “the Rule” for short. The toolkit will help answer the following questions:

- What is community living?
- What is an institution?
- How do institutions hurt people with disabilities?
- What are home and community-based services (HCBS)?
- How does the government pay for HCBS?
- What does the HCBS Rule say?
- How was the HCBS Rule made?
- What rights does the HCBS Rule give me?
- What rules do HCBS providers have to follow?
- What rules do states have to follow?
- Can my rights get taken away under the HCBS Rule?
- When do I get my rights from the HCBS Rule?
- What can I do if someone tries to take away my rights?
- What can I do to fight for our rights under the HCBS Rule?

2. Community Living

What is community living?

People with disabilities don't want to live in separate places built for us. We 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. It can be any place where people with disabilities live with people without disabilities.

Community living means having autonomy. Autonomy is the right to make our own choices about our lives, rather than someone else making choices for us.

If we have autonomy, we can make choices like:

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

What is an institution?

Some disabled people don't live in their communities, but instead in institutions. 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 run by the people who work there, not by the people who live there. People living in institutions usually can't leave the institution whenever they want to. They usually can't decide how they want to spend their time. 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 lives in an institution, it is much harder for them to exercise their rights. When someone lives in their community, it is much easier for them to exercise their rights.

There are a lot of myths about institutions and people with disabilities. Here are the facts about institutions. You can use these facts to tell people the truth about institutions.

#1: Institutions are never good for people with disabilities.

Some institutions look ugly on the outside and inside. They are big buildings with too many people in them. They do not give people who live there much to do. People there might get sick a lot.

Other institutions look pretty on the outside and inside. They look like college campuses, farms, apartments, or regular houses. They give people who live there a lot of things to do. People there get sick less.

Both kinds of institutions are bad.

Both kinds of institutions keep people with disabilities isolated from our communities. Both kinds of institutions take autonomy and choice away from people with disabilities. Both kinds of institutions hurt people with disabilities.

#2: Nobody needs to live in institutions.

Everyone can live in the community!

People with disabilities have different support needs. Some people might need more support than others. Some people say that people with high support needs have to live in institutions. They say that only people with low support needs can live in the community.

This is not true. People with high support needs can live in the community. People with high support needs fought for the right to live in the community.

In 1999, two women living in an institution went to the **Supreme Court**. Their names were Lois Curtis and Elaine Wilson. They said that they had the right to live in the community. The Supreme Court has the final say on how laws work. The Supreme Court said that the women were right. This was called the ***Olmstead decision***.

Lois and Elaine had intellectual disabilities. They had high support needs. They did just fine living in the community!

#3: Everyone can make choices.

Some people say that people who can't make choices need to live in institutions. This isn't true - because everyone can make choices. Nobody needs to live in an institution!

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. This doesn't mean they need to live in an institution. It means we need to take more time and work harder to find out what their choices are.

All of these beliefs about why we need institutions are false. We should work so that **nobody** has to live in an institution.

3. What Is the HCBS Rule?

What are home and community-based services (HCBS)?

Medicaid is a health care program in the United States. Medicaid is run by the government. Every state has its own Medicaid program.

Medicaid helps people get health care if they don't have a lot of money. Lots of disabled people use Medicaid. You can learn more about Medicaid in our [Medicaid Toolkit](#).

Medicaid programs work with **providers**. Providers are people or places that give you health care or services. Some types of providers are doctors or hospitals.

Medicaid pays for **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, and personal care assistants that help you do things in your house.

There are different kinds of LTSS providers. 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)**.

When did the U.S. government start paying for HCBS?

When Medicaid pays for HCBS, it helps us live in our communities. It helps us live the same kinds of lives as everyone else.

Medicaid used to not pay for HCBS. People could only get services in institutions.

This made it harder for us to make choices.

Medicaid first started paying for HCBS in the 1980s. The U.S. government added a new section to a law called the **Social Security Act**. The Social Security Act contains rules which instruct the government on how to run its health care programs, including Medicaid. The new section said that Medicaid money could be used to pay for HCBS.

There were still problems. States have to pay for LTSS in institutions. If you need LTSS services, you can get them in an institution right away.

States don't have to pay for HCBS. The state can decide whether or not they want to put HCBS in their Medicaid program. They can decide to only spend a certain amount of money on HCBS, even if that means some people don't get services. They can make waiting lists. This means some people have to wait a long time before they can get HCBS.

When someone is on the waiting list, they don't get services. Instead, they have to wait until their name comes up next on the list to get services. The same people could get services in an institution right away—but they want services in the community.

So they wait on the waiting list. They can be on the waiting list for many years.

What is the HCBS Rule? Why did CMS pass the HCBS Rule?

There was another reason Medicaid needed to create the HCBS Rule.

Medicaid was paying for HCBS, but had nobody decided what "home and community-based services (HCBS)" actually were. That meant that Medicaid money for HCBS was going to places that said they gave people services "in the home and community"—but they were actually institutions.

The places would say that they weren't institutions because:

- They let people with disabilities choose what to eat for breakfast
- They let people with disabilities live in a house instead of a hospital building
- They let people with disabilities go out to the movies sometimes

But these places still took away our freedom. They still kept us away from our community. They were still institutions, but they got money meant for HCBS.

Some people wait a long time to get HCBS. They wait for such a long time because they want to live in the community, not an institution. If some institutions say they are HCBS, people could wait for years for community services, and then still end up in places that are like institutions. It doesn't matter that they waited so long for HCBS. This isn't fair!

For example:

Lee waited for HCBS for 5 years. Their state Medicaid program told Lee that they could finally get HCBS! Lee moves to a group home. The group home is run by a provider called Sunshine Inc.

Sunshine Inc. doesn't let Lee go out when they want to. Lee only gets to be around other people with disabilities. Sunshine Inc. is supposed to give people HCBS, but Sunshine Inc. is an institution! Lee waited a long time for HCBS, but they still ended up in an institution.

The **HCBS Rule** was made to stop this from happening. The HCBS Rule says which services **are** HCBS. It also says which services **are not** HCBS. It makes sure Medicaid doesn't give HCBS money to institutions.

The HCBS Rule helps us live in our community, get the kind of services we want, and make sure places that say they provide HCBS actually provide HCBS.

How was the HCBS Rule made?

The HCBS Rule came out in 2014. Making a new rule takes a lot of steps.

It started when people with disabilities spoke with CMS. **CMS** is the U.S. government office that runs Medicaid. We told CMS that HCBS money was getting used by institutions, and CMS said that was a problem. CMS wanted to make sure the money helps us live in the community.

CMS listened to people with disabilities. CMS also talked with other groups. They talked with lawyers, HCBS providers, and advocacy groups. Everyone agreed that CMS needed to make a rule.

Next, CMS wrote up a draft of the HCBS Rule. They let everyone know about the draft and gave everyone time to read it.

People commented on the draft to let CMS know if they thought parts of the Rule should be changed. They let CMS know if anything was missing. More than 2000 people submitted written comments on the Rule. CMS got lots of ideas about how to improve the rule. CMS used a lot of those ideas and wrote the final Rule.

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.

4. 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.

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

Community Living

The Rule says that HCBS must be given to you in the community. That means you have the right to community living.

You have the right to live in the community and go out into the community. You have the right to try to get the same kinds of jobs as people without disabilities. You have the right to decide how to spend your money and how you spend your free time. You have the right to get healthcare services in the community.

You can learn more about community living 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, so 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 need to be given more than one choice, and you can't be forced to have a roommate or live in a group home.

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 places like this. 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.

Choosing Where to Get Services

You have the right to choose where you get HCBS.

A lot of the services we need take place in our homes. For example, we may need help getting dressed or taking a bath. Those things usually happen where we live. But, you can also get HCBS outside your home. For example, if the person needs help buying groceries, some people might choose to have their helper come to their house. Other people might decide to meet their helper at the grocery store. You get to choose what works best for you.

You don't have to get HCBS in places that are just for people with disabilities. You can also choose to get HCBS somewhere that is for everyone.

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 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 document that explains what kind of services you get. The HCBS Rule says you have a right to a person-centered plan.

The Rule says a person-centered plan has to follow some rules, or it isn't really a person-centered plan.

The most important rules are:

- The plan is written during a meeting.
- You have to be at the meeting, and you are in charge of the meeting.
- The meeting can have your providers, helpers, and anyone you want at the meeting.
- The plan must be signed by everyone who works on the plan.
- The plan has to explain who will make sure that 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. You get to choose who will be at the meeting. They have to help you figure out how to get what you want and need.

You have a right to a **case manager**. A case manager helps you write your plan and 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 any help you need to understand it. You can get help reading the plan. You can ask for information about the plan in language that is easier to understand.

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

Freedom

You have the right to freedom. Freedom means that you make your own choices about your life. Real freedom means real choices. This means that you can make 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.

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. Brian 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.

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.

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 and 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 that if they get HCBS money, 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 so that it solved the 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, 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 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 make sure that providers are following the HCBS Rule and that the states are following it themselves. They make things harder for people with disabilities, who want our rights to be respected.

Here are some facts about the HCBS Rule. You can use these facts to 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 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.

#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 if they need 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. 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.

HCBS Transition Plans

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

- The state has to look at all of the rules it already has. They have to figure out which of their rules already follow the HCBS Rule. They have to figure out which rules don't follow the HCBS Rule. They have to make a plan to fix the ones that don't follow the Rule.
- The state has to figure out how to tell whether or not a provider is following the HCBS Rule. They then have to figure out how to fix providers that don't follow the Rule.

Making an HCBS transition plan requires many different steps. First, the state has to let people know they are making an HCBS transition plan. People can send their state written comments. The comments say what the person thinks should be in the state's plan. The state puts 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 new draft to people in their state. They get ideas from people like you and me. The state puts those ideas into their new draft. Then, the state sends CMS the new 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 CMS says the draft 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. At this point the transition plan is done!

States need to make sure they follow the plan and that everyone in the state follows the HCBS Rule.

Transition plans can take a long time to make. Right now, only 13 states have finished their plan. We still have a long way to go before all the states are following 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 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**.

The HCBS Rule says which kinds of 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, and talk to the people living there. The state then decides whether or not these places follow the HCBS Rule.

They can decide a place doesn't follow the HCBS Rule. That place won't get HCBS money.

Or, they can decide a place does follow the HCBS Rule. 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 has a limited amount of money to spend on HCBS. We want that money to go to services in the community, not to services in institutions. The HCBS Rule makes sure that money does go 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.

5. Fighting For Your Rights

Can my rights from the HCBS Rule get taken away?

The HCBS Rule gives you rights. Sometimes, those rights can get taken away, but it is very hard.

There are rules about breaking the HCBS Rule. The only parts of the Rule that can get broken are the ones for provider-owned settings. 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 with other people getting HCBS. 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. Miguel gets HCBS in a group home. His provider owns the group home. He lives in a provider-owned setting.

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 from eating so much. Miguel has other things he wants to do besides eating. He likes going to work and the movies.

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. That means breaking part of the HCBS rule.

Miguel calls his person-centered planning team together. They have a meeting.

Miguel talks about his problems with eating. 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. Now he can do the other things he wants to do during the day.

When do I get my rights from the HCBS rule?

Right to A Person-Centered Plan

Right now, you have the right to have a person-centered plan. If you get HCBS and don't have a person-centered plan, that is wrong!

What about all my other rights?

You should get your other rights in 2022.

States are still not following all the parts of the HCBS Rule. Right now, your state is getting ready to follow the Rule. They are helping your provider get ready, too.

States were supposed to follow all the parts of the Rule by 2020, but the U.S. government pushed back the date. Now, states have until 2022 before they have to follow all of the Rule.

This could change! Be sure to check and see if the date changes.

What can I do if someone tries to take away my HCBS rights?

There are lots of different people you can talk to about your rights.

You can talk to your state's Protection and Advocacy (P&A) organization

P&A's help people with disabilities fight for our rights. They make sure states follow disability-related laws. There is a P&A in every state. You can find your P&A by going to <https://www.ndrn.org/about/ndrn-member-agencies/>

You can talk to your state's developmental disabilities (DD) agency.

DD agencies run the state's Medicaid programs. That means they run the state's HCBS program. They also run other programs for people with intellectual and developmental disabilities. You can find your DD agency by going to <https://www.nasddds.org/state-agencies/>.

You can contact ASAN!

You can contact the Autistic Self Advocacy Network at info@autisticadvocacy.org. We can help you advocate for your rights.

How can I make sure states follow the HCBS Rule?

How can I find out what is happening in my state?

You can look at the HCBS Advocacy Coalition website. They keep track of what every state is doing to follow the HCBS rule. Their website is [HCBSAdvocacy.org](https://www.hcbsadvocacy.org)

You can email the Autistic Self Advocacy Network. We have a list of people you can talk to about what is happening in your state.

You can also contact your P&A or DD agency.

What can I do?

You can look at your state's HCBS transition plan. You can let your state know what you think about the plan. Your state could put your thoughts into their plan!

You can find out what places in your state got heightened scrutiny. You can let your state know if you think those places follow the HCBS Rule. You can tell your state if you think they missed any places.

You can also talk to your state DD agency. Tell them why the HCBS rule is important to you. Ask them how they will make sure your state follows the HCBS Rule.

Who can I work with?

Information about your state and the HCBS Rule can be hard to find. It can be confusing. There are groups that can help.

Here are some groups that fight to make sure the HCBS Rule gets followed:

- The Autistic Self Advocacy Network
- The Arc of the United States and its local chapters
- The National Disability Rights Network

You can also work with your state's **Developmental Disabilities (DD) Council**. DD councils work to help people with developmental disabilities. They figure out problems in the state 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. DD councils can help people learn more about the HCBS Rule. They can make events to teach us about our rights.

6. 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.

CMS

The government office that runs Medicaid.

Developmental Disabilities (DD) Agencies

Groups that run the state's Medicaid programs. They also run other programs for people with intellectual and developmental disabilities.

Developmental Disabilities (DD) Councils

Groups in each state that work to help people with developmental disabilities. Every DD council has to have people with developmental disabilities on it.

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 disabled people 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.

LTSS

Services that help disabled people live our everyday lives. Some kinds of LTSS are job coaches, transportation, or an in-home helper.

Medicaid

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

Olmstead decision

A decision the Supreme Court made. It says people with disabilities have a right to live in the community.

Person-Centered Plan

A paper that says what kind of services you get.

Protection and Advocacy (P&A) organizations

Places that help people with disabilities fight for our rights. They make sure states follow disability laws.

providers

People or places that give people 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.

Social Security Act

A law that tells the government how to run health care programs.

Supreme Court

The U.S. court that has the final say on how laws work.

tenants

People who rent houses.