



# The HCBS Settings Rule: Talking Points

# What is this guide for?

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This is a guide for writing newspaper op-eds about the Home and Community Based Services (HCBS) Settings Rule. The HCBS Settings Rule is a rule the government made that gives people with disabilities more rights when we receive services in our communities. The HCBS Settings Rule went into effect (started working) on March 17, 2023. The HCBS Settings Rule is a very important rule. But many people with disabilities don't know about the HCBS Settings Rule.

You can help! You can write an op-ed for your local newspaper. An op-ed is an article that tells people about your opinion on something. In an op-ed, you try to convince people to agree with you and to take action. You can read more about writing op-eds in ASAN's toolkit "[Sharing Your Story for a Political Purpose.](#)" You can also check out [The Op-Ed Project](#). That is a website that helps people learn how to write op-eds.

Here is a basic outline of what you should include in an op-ed about the HCBS Settings Rule. We go into each point in much more detail in each guide.

- What home and community based services are
- What the HCBS Settings Rule is and what the HCBS Settings Rule does.
- The rights people get from the HCBS Settings Rule.

- Why we need the HCBS Settings Rule.
- When the HCBS Settings Rule went into effect (started working).
- What a state transition plan is and how to find your state's transition plan
- What a corrective action plan (CAP) is and how to find if your state has a CAP.
- How to figure out what next steps your state and service providers in your state need to take.
- How to help advocate for your and/or other people's rights.

# What is the HCBS Settings Rule?

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

People with disabilities want to live in the community with everyone else! We don't want to live in hospitals or other institutions or separate places "just for us"! When we live in the community, we can make more choices about our lives. We can choose things like where we go to work or school, how we spend our free time, who our friends are, how we decorate our living spaces, and more.

Some people with disabilities receive **long-term supports and services (LTSS)**. LTSS help people with disabilities live our everyday lives. Some examples of LTSS are: an in-home helper (like a direct support worker or personal care attendant), transportation (like paratransit, bus passes, or adapted vehicles), and support at work (like a job coach). People can get LTSS in an institution or in the community. When people get LTSS in the community, it is called **home and community based services**, or HCBS.

# What does the HCBS Settings Rule do?

The Home & Community Based Services Final Regulation (which we will call the **HCBS Settings Rule**, or just the **Settings Rule**) is a rule the US government made in 2014. The part of the government that made the Settings Rule is the **Centers for Medicare and Medicaid Services**, or CMS. The Settings Rule says that when people receive HCBS, they have certain rights. The Settings Rule also says that HCBS have to meet certain minimum standards.

Here are some examples of rights the Settings Rule gives people receiving HCBS:

- The right to live in the community alongside people who don't get HCBS.
- The right to choose where they live, and where they get HCBS.
- The right to get a plan that says what services they get.
- The right to have freedom to make choices, both big and small.
- The right to have respect and privacy from people providing them HCBS.

- The right to not be restrained (held or tied down) or secluded (locked in a room by themselves).

Some people who receive HCBS live in provider-owned settings, like group homes or assisted living centers. People living in provider-owned settings get more rights under the Settings Rule, such as:

- The right to have a lease or equivalent document for their living space.
- The right to have the same rights and responsibilities as a tenant without a disability in their city.
- The right to have a lock on their bedroom or unit door.
- The right to pick their roommate, if they have a roommate.
- The right to physical accessibility in their living space (like having a wheelchair-accessible apartment)
- The right to have visitors at any time.
- The right to eat whenever they want.
- The right to set their own bedtime, wakeup time, and daily schedule.

The Settings Rule says that (with limited exceptions) if a provider isn't ensuring that people receiving services from that provider have these rights, the provider is not giving people HCBS. People must have these rights in order for the service to be really HCBS.

The Settings Rule also says that institutions can never provide HCBS. Institutions are places like hospitals, psychiatric facilities/IMDs, ICFs, and nursing facilities.

## **Why does the Settings Rule matter?**

The Settings Rule matters because it defines what people's rights are when receiving HCBS. The rights we talked about in the section "What does the Settings Rule do?" are very basic, but they are also very important. Until now, there hasn't been a national "Bill of Rights" for people receiving HCBS or rules about what rights people have when they receive HCBS. There haven't been basic standards for what HCBS needs to be and needs to provide. The Settings Rule changes this.

Up until now, many people receiving HCBS haven't had these rights. When people don't have these rights, it is very easy for so-called "HCBS" settings to turn into mini-institutions. In these mini-institutions, it might look like people are receiving HCBS. But the people in the mini-institutions don't have rights. They don't have control over their lives. The Settings Rule gives people basic rights that help them stay in control of their lives and services.

# When does the Settings Rule go into effect?

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The Settings Rule went into effect (started working) on March 17, 2023.

There are some rights that people receiving HCBS may or may not have had when the Settings Rule went into effect on March 17, 2023. This is because, due to the COVID-19 pandemic, states might need extra time to put these rights into effect. These rights are:

- The right to live in the community alongside people who don't get HCBS.
- The right to have a job that they choose
- The right to have a private house, apartment, or room all to themselves
- The right to choose their roommate, if they have a roommate

States who needed extra time to put these rights into effect needed to submit a **Corrective Action Plan**, or CAP, to CMS. We will talk more about CAPs in the section "What have states had to do so far?"



# What have states had to do so far?

So far, states have had to submit **transition plans** to CMS. 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.

Remember, CMS originally made the Settings Rule in 2014. So states have had almost 10 years to submit their transition plans to CMS. Every state has submitted at least a first draft of their plan to CMS. Some states have gotten final approval from CMS, which means CMS said those state's plans are ready to go. Other states have only gotten initial approval from CMS. That means those states need to make changes to their transition plans before they get final approval from CMS.

Because of the COVID-19 pandemic, some states need extra time to meet certain parts of the Settings Rule. We talked about the rights states can ask for more time on in the last section. States who ask for more time to meet certain parts of the Settings Rule need to submit a Corrective Action Plan, or CAP, to CMS. A CAP is a plan for how providers in the state will be able to eventually follow all the parts of the HCBS Settings Rule. You can read more about which states have asked for CAPs at [CMS's page on state transition plans](#).

# What do states have to do now?

What your state has to do now depends on the state and whether it has a CAP.

If your state does not have a CAP, it needs to be in full compliance with the HCBS Settings Rule. That means your state needs to be actively looking for and dealing with providers who are not following the Settings Rule. Your state needs to be looking into complaints people make about their providers not following the rule. Your state needs to be identifying and dealing with providers who are not following the Settings Rule. Your state needs to be doing this for all the parts of the Settings Rule.

If your state does have a CAP, it needs to be working to follow its CAP. Remember, a CAP outlines what the state will do to make sure providers eventually will follow all the parts of the Settings Rule. So your state needs to be getting ready to enforce the rights that its CAP talks about. Your state also has to be in compliance with the rest of the parts of the Settings Rule. For example, your state has to be enforcing the right to respect and privacy, because that is a part of the Settings Rule states are not allowed to have CAPs about.

# How can I find out what my state is doing?

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You can find out what your state is doing to work on the HCBS Settings Rule in a few different ways. You can look at your state's transition plan (and CAP, if your state has one). You can work with people and groups in your state to understand your state's transition plan (and CAP). You can also contact the part of your state's government that works on the Settings Rule with questions and more information.

## Look at your state's transition plan (and CAP, if applicable)

You can find your state's transition plan (and CAP, if your state has one) on [CMS's page on state transition plans](#). Transition plans and CAPs can be hard to read. We will talk later about who you can get help from to understand your state's transition plan (and CAP) in a later section.

## Work with people and groups to understand your state's transition plan (and CAP)

There are different groups in each state who work on disability issues. Here are some of these groups:

- Protection and Advocacy groups (P&As). P&As are groups that help people with disabilities with legal issues. There is one P&A per state. You can find your state's P&A at the [NDRN Member Agencies page](#).
- Centers for Independent Living, or CILs. CILs are groups that provide resources to help people with disabilities live in the community. There is usually more than one CIL per state. You can find your local CIL at the [ILRU Directory of CILs](#).
- Developmental Disabilities Councils (DD Councils). DD Councils are groups that work to help people with intellectual and developmental disabilities. DD Councils advise the state government on issues that affect people with intellectual and developmental disabilities. There is one DD Council per state. You can find your state's DD Council at the [NACDD State DD Councils page](#).

- Self-advocacy groups. Self-advocacy groups are groups of people with disabilities, usually people with intellectual and developmental disabilities, that work on disability issues. There are usually multiple self-advocacy groups in each state. You can find your local self-advocacy group at [People First's listing of groups](#) or [Self-Advocacy Online's listing of groups](#). You can also check to see if you have an [ASAN affiliate group](#) in your state.

Many of these groups are working on translating state transition plans or CAPs into simpler language. Or they may have resources that explain what some of the language in the transition plans or CAPs mean. If you need help understanding your state's transition plan or CAP, contact one of these groups. Even if the group you contact can't help you, they should know who can.

## Contact the part of your state's government that works on the Settings Rule

Each state has a part of its government responsible for working on the HCBS Settings Rule. The name of this department or agency varies by state. Some common names are "Department of Human Services," "Department of Health and Human Services," or "Department of Social Services."

To find the contact information for the part of your state's government that works on the HCBS Rule, go to [CMS's page on state transition plans](#). Find your state in the list. Then, click on the link that says "[State name] Proposed Plan." This will take you to your state's webpage for their transition plan.

The transition plan should have a way to submit questions and comments on the transition plan. This may be a web form, an email address, a phone number, or a mailing address. You may have to scroll down to find the contact information for submitting questions and comments on the transition plan.

If you can't find contact information for submitting questions and comments on the transition plan, look for the general contact information for the government department or agency. Often, if you scroll to the bottom of the page, there will be contact information listed.

# How can I make sure my rights are protected under the HCBS Settings Rule? How can I make sure other people's rights are protected under the Settings Rule?

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If you get HCBS, you have rights under the HCBS Settings Rule! 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?", available in both [Easy Read](#) and [plain language](#).

There are some things everyone can do to help people who receive HCBS, whether they receive HCBS themselves or not. Everyone can:

- Tell people about their rights
- Advocate for states to enforce the Settings Rule
- Help people report violations of their rights to provider agencies
- Help people report violations of their rights to the state, CMS, or the P&A



## Telling people about their rights

You can tell other people about their rights. A lot of people, including a lot of people who receive HCBS, don't know about the Settings Rule or the rights the Settings Rule gives them. People can't advocate for rights they don't know about. You can use ASAN's toolkits and guides on the Settings Rule to help teach people about their rights.

## Advocating for states to enforce the Settings Rule

You can advocate for your state to enforce the Settings Rule. One way to do this is to contact your elected officials at the state level, like your state's governor and your legislators in the state legislature. You can ask them to make sure your state enforces the Settings Rule.

You can also contact the part of your state's government that works on the Settings Rule. You can let them know what you think about how they are making sure providers follow the Settings Rule. Find out how to contact the part of your state's government that works on the Settings Rule in the section "Contact the part of your state's government that works on the Settings Rule."

## Help people report violations of their rights to provider agencies or case managers

A violation is when a service provider doesn't give a person their rights under the Settings Rule. Some examples of violations include:

- A group home forcing everyone living there to all go on the same trips at the same time
- An assisted living facility making everyone living there eat dinner at the same time
- A support worker refusing to give a person privacy and saying the person must have their door open at all times

People who get HCBS can report violations of their rights to their provider agencies or case managers. We talk more about both these options in our guide "Who can I talk to if someone isn't respecting my rights?" available in both [Easy Read](#) and [plain language](#). We will talk briefly about both options here.

**Provider agencies:** In general, service providers work for agencies. Agencies are companies that manage and employ providers. If a person receiving services has a problem with one of their providers, they should complain to the agency the provider works for. They can do this by going through the agency's grievance (complaint) process. You can read more about how to start that process in "Who can I talk to if someone isn't respecting my rights?"

**Case managers:** A case manager is someone who helps a person manage the services they receive. Case managers help people make sure their services work for them. If someone is having a problem with their providers, they should talk to their case manager. In many cases, the case manager can help the person resolve the issue.

## Help people report violations of their rights to the state, CMS, or the P&A

You can also help people report violations of their rights to their state government, CMS, or their state's P&A. Remember, CMS is the part of the US government that made the Settings Rule. P&As are legal groups that help people with disabilities. There is one P&A in every state.

Here is how to report violations of rights to the state government, CMS, or the state P&A:

**State government:** Unfortunately, it can be difficult to figure out the right person or group to report violations to. You will want to report to the part of the state government that works on the Settings Rule. Some common names for this department are "Department of Human Services," "Department of Health and Human Services," or "Department of Social Services." Follow the steps in the section "Contact the part of your state's government that works on the Settings Rule."

**CMS:** People who want to report violations of their rights should contact their state government before contacting CMS. But if your state does not take action to help people with rights violations, you can contact CMS. Here is the CMS contact information:

- Phone Toll-Free: 877-267-2323
- Phone Local: 410-786-3000
- TTY Toll-Free: 866-226-1819
- TTY Local: 410-786-0727
- Medicaid.gov Mailbox: [Medicaid.gov@cms.hhs.gov](mailto:Medicaid.gov@cms.hhs.gov)

**P&As:** P&As can help people with disabilities report rights violations to the correct part of the government. P&As may have an intake form on their website, or a phone number or email address to contact. You can find your state's P&A on [the NDRN website](#).