



ASAN

AUTISTIC SELF ADVOCACY NETWORK

Settings

Rules Resources

**What are my rights in the
type of setting I live in?**

With checklists



Institutions

What is an institution?

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.

What are my rights if I live in an institution?

The HCBS Rule does not say what your rights are in an institution. The HCBS Rule only talks about what your rights are when you get services in your home or the community. But if you live in an institution, you still have rights! You have rights under the **Olmstead decision**.

The *Olmstead* decision was an important Supreme Court case. The *Olmstead* decision said that people with disabilities have the right to live in our communities. We don't have to live in institutions just because we have disabilities. If you want to move out of an institution, you can get help with this. There are a few groups you can contact for help with moving from an institution to the community.

Your state's Protection and Advocacy organization (P&A)

Protection and Advocacy organizations (P&As) help people with disabilities fight for our rights. P&As make sure states and other people or groups, like institutions, 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/>

Money Follows the Person (MFP) programs

Money Follows the Person (MFP) is a program that gives states money to move people from institutions to the community. 43 states and Washington, D.C. have MFP programs. MFP programs can help you move out of an institution and into the community. You can find out whether your state has a MFP program here: <https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/>

[list-of-money-follows-person-grantees/index.html](https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/). You can also find out more about your state's MFP program by doing a web search for "[your state] money follows the person program."

I have an HCBS waiver. Should I still be living in an institution?

An **HCBS waiver** is a document. An HCBS waiver says you can get services from places besides in an institution. It says you want to get HCBS instead. And it says Medicaid will pay for the HCBS. If you have an HCBS waiver, you should not be living in an institution! Nobody should live in an institution. But if you have an HCBS waiver, Medicaid says you can get services in the community. That means you should be able to move into the community as quickly as possible. If you have an HCBS waiver and you live in an institution, you can contact your state's P&A. Your state's P&A can help you fight for your right to live in the community.

You can also contact your state's developmental disability (DD) agency. **DD agencies** run state HCBS programs. DD agencies also oversee institutions in states. They also run other programs for people with intellectual and developmental disabilities. You can find your DD agency by going to <https://www.nasdds.org/state-agencies/>

Heightened Scrutiny settings: Places that look a lot like institutions

What is a heightened scrutiny setting?

There are some places that can't follow the HCBS Rule. Institutions can never follow the HCBS Rule. So institutions can never get HCBS money. Other places can follow the HCBS rule.

But some of these places look like institutions. States need to make sure these places aren't institutions. They do that by giving these places **heightened scrutiny**.

Heightened scrutiny is a process. In heightened scrutiny, settings that look like institutions get to prove they are not institutions. The HCBS Rule says which places

get heightened scrutiny. Some places that get heightened scrutiny are:

- Places that used to be institutions.
- Places in the same building where an institution is.
- Places that are next to an institution.
- Places far away from the community.
- Places where only disabled people live.

What is a heightened scrutiny setting review?

A **heightened scrutiny setting review** is when states look closely at places that get heightened scrutiny. States take a closer look at these places. They go visit these places. They talk to people living there. They decide whether or not these places follow the HCBS Rule.

A state can decide a place doesn't follow the HCBS Rule. Then, that place won't get HCBS money. Or, a state can decide a place does follow the HCBS Rule. Then, that place can get HCBS money. States write down what they decide in their HCBS transition plan. Then, CMS decides if they agree with the states. (CMS is the part of the government that made the HCBS Rule.)

CMS will also visit some places that get heightened scrutiny in each state. CMS talks to the people living in those places. CMS decides whether or not these places follow the HCBS Rule.

What rules do heightened scrutiny settings have to follow under the HCBS Rule?

States and CMS work together to decide which places that get heightened scrutiny can get HCBS money. If a place that got heightened scrutiny can get HCBS money, that place has to follow the same rules as other provider-owned settings. (A provider owned setting is when your HCBS provider owns the place where you get HCBS.) These rules include giving people living in those places certain rights. If you live in a place that got heightened scrutiny and is getting HCBS money, you have rights like:

- The right to a person-centered plan. A person-centered plan is a paper that

says what services you get.

- The right to a case manager. A case manager is someone who helps keep track of your services. They make sure that you get the services that are in your person-centered plan.
- The right to privacy and respect from service providers.
- The right to freedom from restraint and seclusion. Restraint is when someone stops someone else from moving around. Seclusion is when someone locks someone else in a room by themselves. Restraint and seclusion are dangerous.
- The right to have control of your own belongings.
- The right to have privacy in your house, apartment, or room
- The right to a house, apartment, or bedroom door that locks.
- The right to freedom to decorate your house, apartment, or bedroom room however you want
- The right to get food at any time
- The right to have visitors at any time
- The right to physical accessibility, like making sure your living space is wheelchair-accessible if you use a wheelchair.
- The right to have a lease agreement or other document that explains what your tenant rights are
- The right to go out into and be part of the larger community
- The right to get a job in the community
- The right to choose to live in a house or apartment by yourself
- The right to choose to live in a house or apartment without other people with disabilities

You can read more about these rights in our toolkit [This Rule Rules!](#) or in our fact sheet "How can I find out what rights I have under the HCBS Rule?"

Provider-owned setting

Some people who get HCBS live in provider-owned settings. A **provider owned setting** is when your 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.

If you live in a provider-owned setting, you have rights like:

- The right to a person-centered plan. A person-centered plan is a paper that says what services you get.
 - The right to a case manager. A case manager is someone who helps keep track of your services. They make sure that you get the services that are in your person-centered plan.
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wheelchair-accessible if you use a wheelchair.

- ❑ The right to have a lease agreement or other document that explains what your tenant rights are
- ❑ The right to go out into and be part of the larger community
- ❑ The right to get a job in the community
- ❑ The right to choose to live in a house or apartment by yourself
- ❑ The right to choose to live in a house or apartment without other people with disabilities

You can read more about these rights in our toolkit [This Rule Rules!](#) or in our fact sheet “How can I find out what rights I have under the HCBS Rule?”

My own home/Family home/not a provider-owned setting

Some people who get HCBS live in places that are not provider-owned settings.

These settings can include:

- ❑ Living on your own in a house or apartment that you own or rent
- ❑ Living with a partner or friends in a house or apartment you own or rent together
- ❑ Living in your family’s home or apartment that your family owns or rents.

If you live in one of these places, you have rights under the HCBS rule.

These rights to include:

- ❑ The right to a person-centered plan. A person-centered plan is a paper that says what services you get.
- ❑ The right to a case manager. A case manager is someone who helps keep track of your services. They make sure that you get the services that are in your person-centered plan.
- ❑ The right to privacy and respect from service providers.

- ❑ The right to freedom from restraint and seclusion. Restraint is when someone stops someone else from moving around. Seclusion is when someone locks someone else in a room by themselves. Restraint and seclusion are dangerous.

- ❑ The right to have control of your own belongings.

To learn more about these rights, check out [This Rule Rules!](#)

You have these rights no matter where you live.

Providers should respect these rights no matter what.

You also have the rights you would have if you lived in a provider-owned setting.

These rights include:

- ❑ The right to privacy in your house, apartment, or room
- ❑ The right to a door that locks
- ❑ The right to to decorate your house, apartment, or room however you want
- ❑ The right to get food at any time
- ❑ The right to have visitors at any time
- ❑ The right to have a lease agreement

You should know that these rights are about your rights with providers.

The HCBS Rule doesn’t talk about your rights with family, partners, or friends.

For example, say you and your friends rent a house together.

You all agree that you won’t decorate the living room without all agreeing on it first.

This does not break the HCBS Rule. It does not have to do with providers.

But say you have an in-home helper.

Your in-home helper tells you that you can’t decorate your room the way you want.

This does break the HCBS Rule. A provider is not letting you have one of your rights.

Living spaces that are not provider-owned settings also do not have to be accessible under the HCBS Rule.

There are other laws that talk about whether living spaces have to be accessible.

For example, if you rent your home, laws like the Americans with Disabilities Act and the Fair Housing Act might apply.

There might also be state laws that apply to your situation.

If you are dealing with housing that is not accessible, you should contact your state's P&A first.

P&As are legal groups that help people with disabilities.

Your state's P&A will have resources on how to make your housing more accessible.

Your state's P&A can also help you file a complaint about your housing to your landlord or to the government.

If you are on an HCBS waiver, you may be able to get home modifications paid for by your waiver. Home modifications are changes to your home to make it more accessible to you. Some examples of home modifications are:

- A wheelchair ramp instead of stairs
- A doorbell that uses lights instead of noise to get your attention
- Grab bars in the bathroom

Not all HCBS waivers will pay for home modifications. It depends on the type of waiver you are on and what the home modification is. If you want to try to get your waiver to pay for home modifications, talk to your case manager first. Your case manager can tell you if your waiver will pay for home modifications.

There may be other programs or agencies in your area that help pay for home modifications. You can contact your local center for independent living (CIL) for more information about these programs. 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>. Your local CIL can also help you apply for these programs.