



Easy Read Edition

This Rule Rules!

The HCBS Settings Rule and You

Part 5: Fighting For Your Rights



NASDDDS

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.



It is very hard for your rights to get taken away.



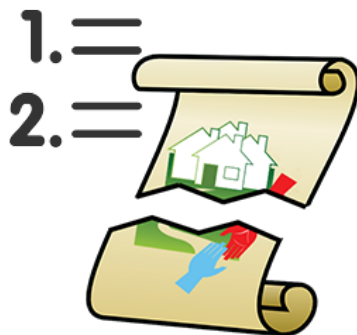
Some people need help being safe.



Sometimes, that help breaks the Rule.



That's the only time the **provider** can break the Rule.



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**.



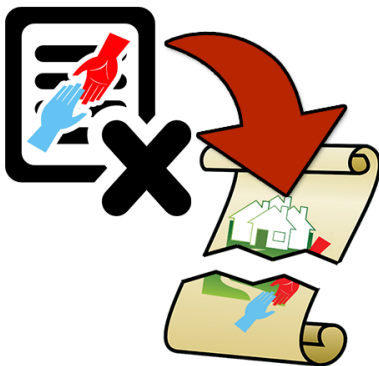
They can't take away your main rights, like your freedom or privacy.



They can't take away your right to live in the community.



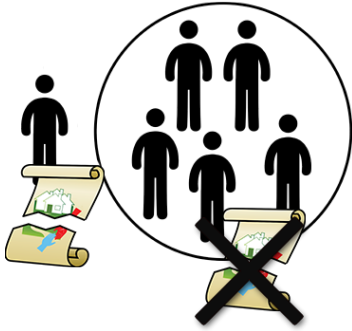
Providers can only break the Rule if they tried other ways to help already.



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**.



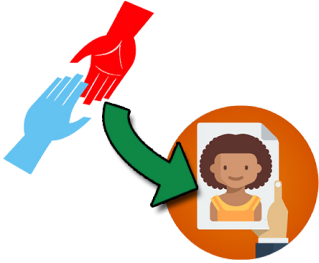
Your provider still has to follow the Rule for everyone else.



This makes sure providers don't try to come up with reasons to break the Rule.



Remember, everyone getting HCBS gets a **person-centered plan**.



The person-centered plan says what kinds of help you get.

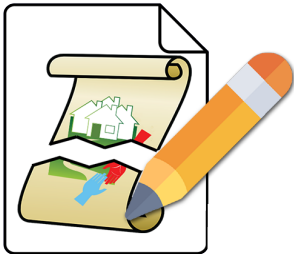


If a provider needs to break the Rule to help you, the plan needs to be changed.

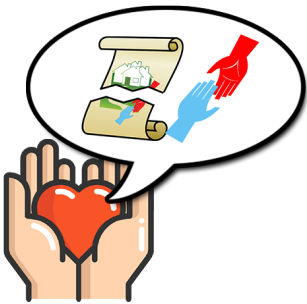


You need to have a meeting to get your plan changed.

At this meeting, your providers have to:



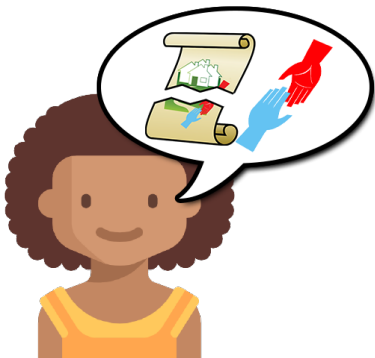
- Write down why they want to break the HCBS Rule.



- Talk to you about why breaking the Rule will help you.



- Tell you about the other ways they tried to help you.



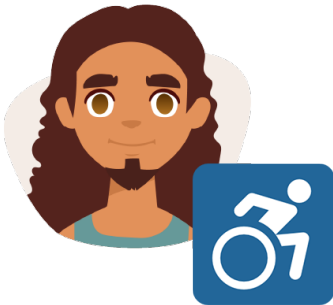
You have to agree that breaking the Rule is the right way to help you.



Once you agree, it gets put in your person-centered plan.



Here is an example of a time someone might break the HCBS Rule:



Miguel has a disability.



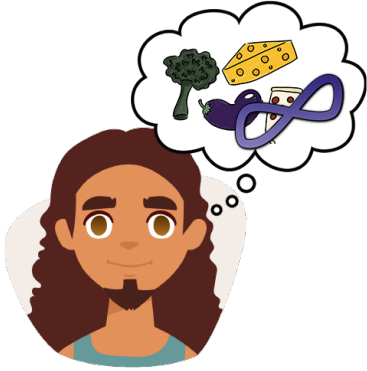
Miguel gets HCBS in a group home.



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 could get food whenever he is hungry.



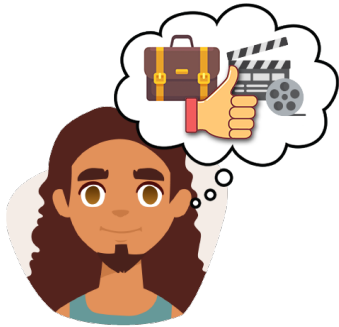
He would never be able to stop eating.



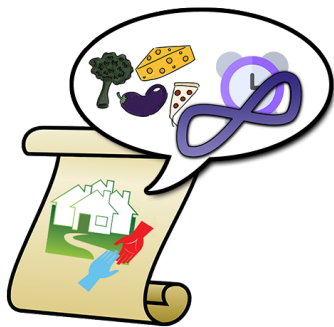
He might get sick from eating so much.



Miguel has other things he wants to do besides eating.



He likes going to work and the movies.



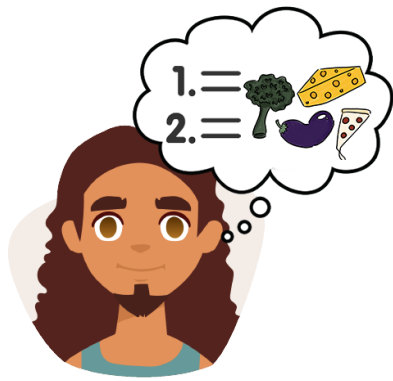
The HCBS Rule says people must be able to eat whenever they want.



This part of the HCBS Rule does not work for Miguel.



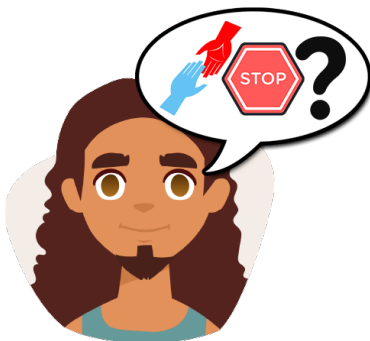
At first Miguel tries to do other things.



He makes his own rules to figure out when to eat.



But 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.



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.



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.



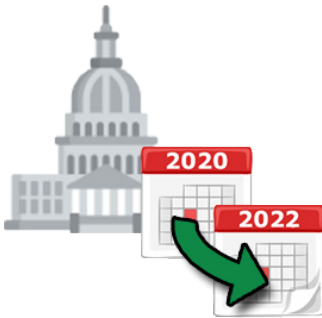
Right now, your state is getting ready to follow the Rule.



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 laws.



There is a P&A in every state.

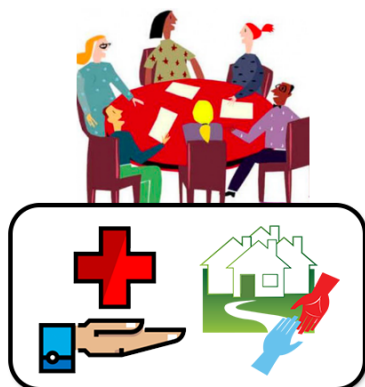


You can find your P&A by going to <https://www.ndrn.org/about/ndrn-member-agencies/>

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?

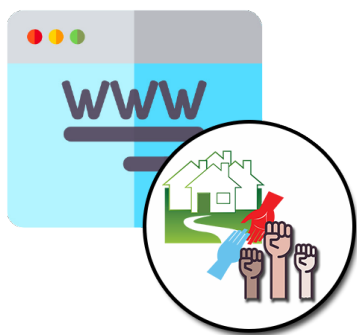
How can I find out what is happening in my state?



You can look at the HCBS Advocacy Coalition website.



They keep track of what every state is doing to follow the HCBS rule.



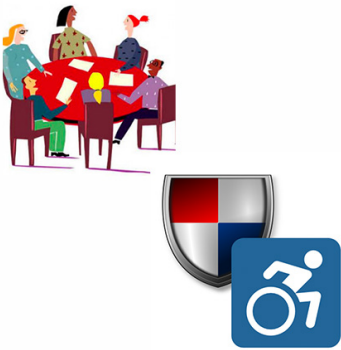
Their website is [HCBSAdvocacy.org](https://www.HCBSAdvocacy.org).



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.

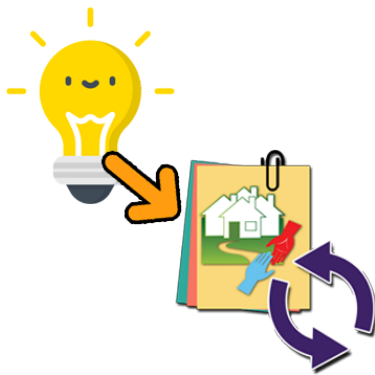
What can I do?



You can look at your state's **HCBS transition plan**.



You can let your state know what you think about the plan.



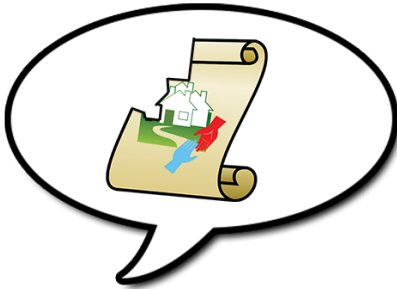
Your state could put your thoughts into their plan!



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 can 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.

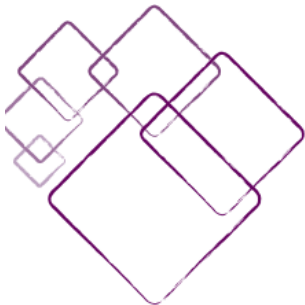
Here are some groups that fight to make sure the HCBS Rule gets followed:



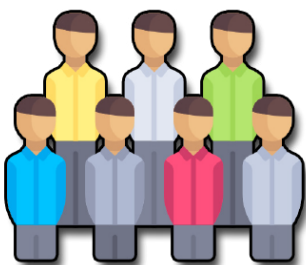
- The Autistic Self Advocacy Network



- The Arc of the United States and its local chapters



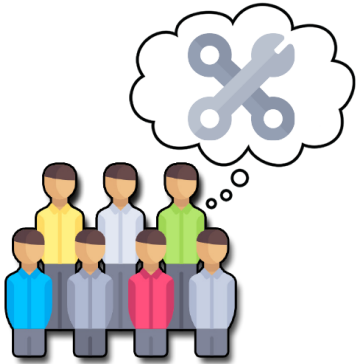
- The National Disability Rights Network



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 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.

Words to Know



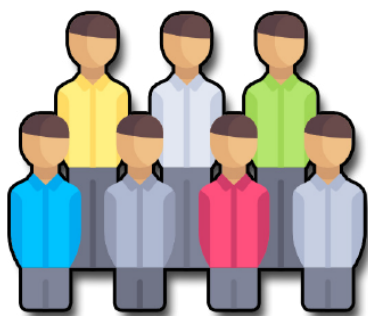
case manager

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



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.



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 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.

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