



NASDDDS

Easy Read Edition

This Rule Rules! **The HCBS Settings Rule** **And You**

Part II: What Is the HCBS Rule?

Words to Know in Part II



CMS

The government office that runs Medicaid.



Community living

Living in the same places as people without disabilities.



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.



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. The HCBS rule says a place is an institution if it has space for 16 or more people with disabilities to live there.



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.



Providers

People or places that give health care. Some types of providers are doctors or hospitals.



Social Security Act

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

Part II: What Is the HCBS Rule?

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



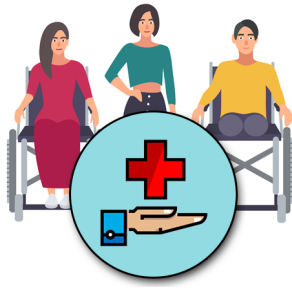
Medicaid is a health care program in the United States.



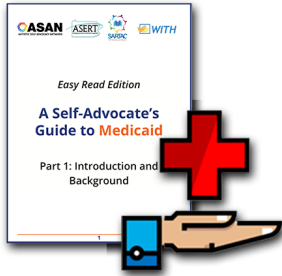
Medicaid is run by the government. Every state has its own Medicaid program.



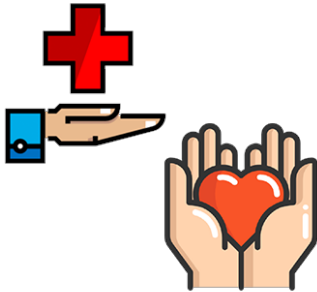
Medicaid helps people get health care if they don't have a lot of money.



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 health care.



Some types of providers are doctors or hospitals.



One thing Medicaid pays for is **long-term services and supports (LTSS)**.



LTSS are services that help disabled people live our everyday lives.

Some examples of LTSS are:



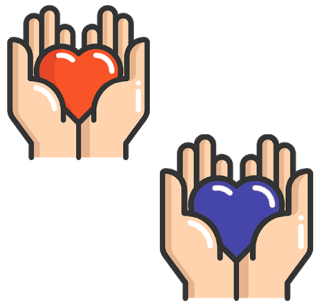
- Job coaches



- Transportation



- An in-home helper



There are different kinds of LTSS providers.



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.



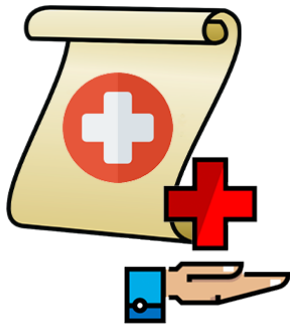
Medicaid first started paying for HCBS in the 1980s.



The U.S. government added a new part to a law called the **Social Security Act**.



The Social Security Act tells the government how to run health care programs.



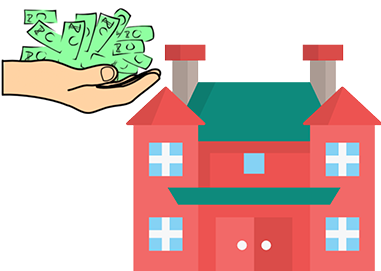
Medicaid is one of the programs under the Social Security Act.



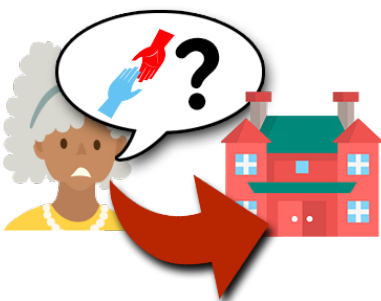
The new part said that Medicaid could pay for HCBS.



But, there were still problems.



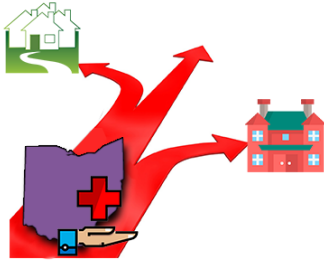
States have to pay for LTSS in institutions.



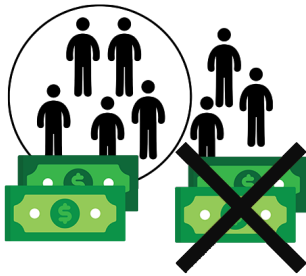
If you need services, you can go into an institution right away.



But states don't have to pay for HCBS.



The state can decide if they want to put HCBS in their Medicaid program.



They don't have to spend enough money for everyone to get HCBS.



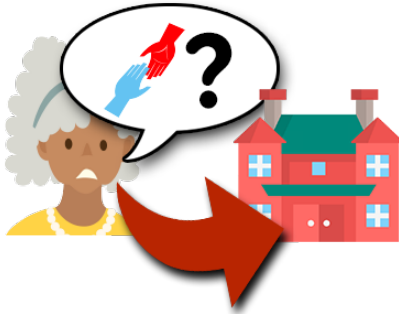
They can make waiting lists.



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.



The same people could go into an institution right away. They could get services.



But they want services in the community.

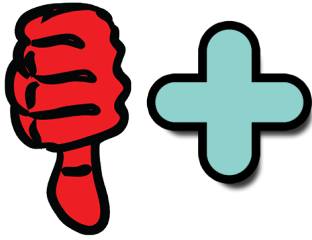


So they wait.



They can wait for many years.

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



There was another problem.



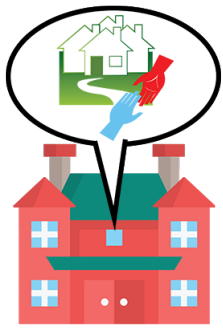
Medicaid was paying for HCBS.



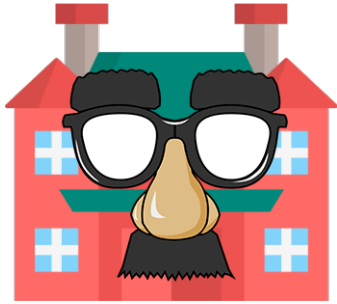
But, nobody decided what “HCBS” actually meant.



Medicaid money for HCBS was going to institutions instead.



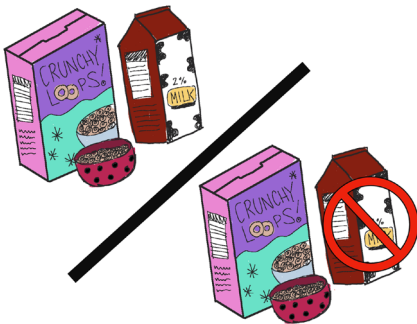
Institutions could say they actually gave HCBS.



Institutions would say they were not really an institution.



They would give reasons like:



- 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 still got money meant for HCBS.



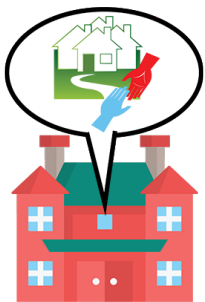
This wasn't fair!



People can wait a long time to get HCBS.



They wait so long because they want to live in the community.



Some institutions say they are HCBS.



So people could still end up in institutions.



It doesn't matter that they waited so long for HCBS.



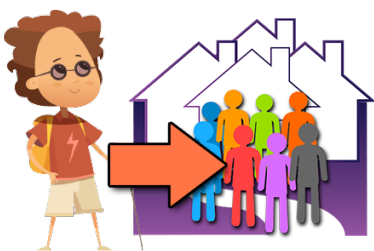
This isn't fair!



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 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 what services **are** HCBS.



It also says what services **are not** HCBS.



It makes sure Medicaid doesn't give HCBS money to institutions.



The HCBS Rule helps us live in our community.



It helps us get the kind of services we want.



And it helps make sure HCBS is actually HCBS.

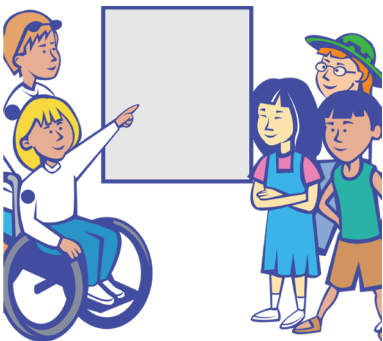
How was the HCBS Rule made?



The HCBS Rule came out in 2014.

1... 2...
3... 4...

Making a new rule takes a lot of steps.



It started when people with disabilities talked to CMS.



CMS is the U.S. government office that runs Medicaid.



We told CMS that HCBS money was getting used by institutions.



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.



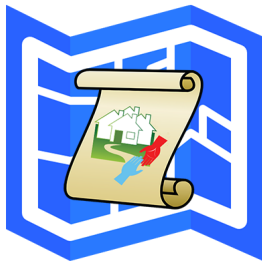
CMS also talked with other groups.



They talked with lawyers, HCBS providers, and advocacy groups.



Everyone agreed that CMS needed to make a rule.



Then, CMS wrote up a draft of the HCBS Rule.



They let everyone know about the draft.



They gave everyone time to read it.



People let CMS know if they thought parts of the Rule should be changed.



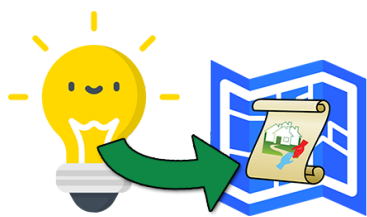
They let CMS know if anything was missing.



More than 2000 people talked to CMS about the Rule.



CMS got lots of ideas about how to make the Rule better.



They used a lot of those ideas.



Then, they wrote the final Rule.



The final Rule is not perfect.



CMS heard from a bunch of different people.



The Rule gave everyone some of what they wanted.



No group of people got everything they wanted.



It was a compromise.

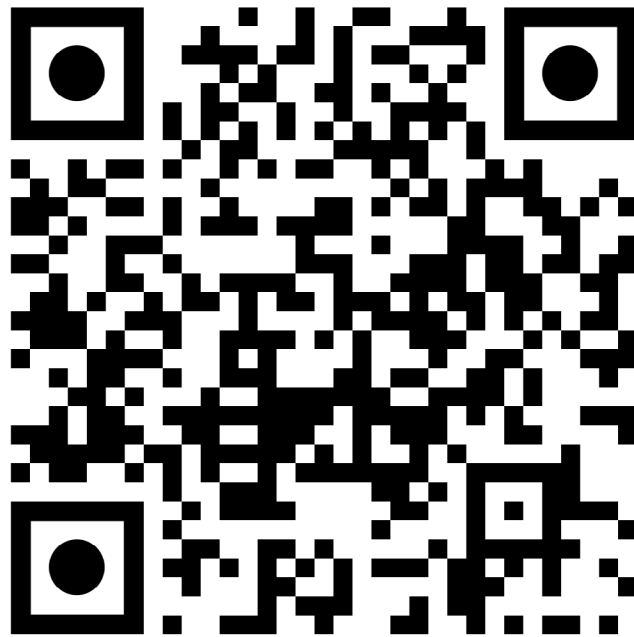


But it is still a very important Rule.

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