



Easy Read Edition

Crisis In Our Communities: Racial Disparities in Community Living

Part 3: Supports in the Community

Words To Know in Part 3



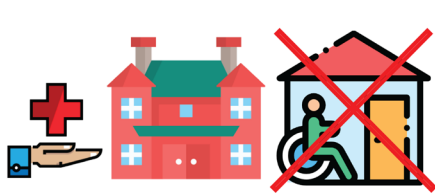
Domestic work

Domestic work is a group of jobs that are usually done in the home. These can include jobs related to cleaning, cooking, and providing supports. Providing home- and community-based services is one kind of job that is called domestic work.



Home and Community Based Services

Home and Community Based Services are a type of LTSS where people get the services they need at home instead of from institutions. For example, help with cooking or cleaning at home. The law says we have a right to get the supports we need as HCBS.



Institutional bias

Institutional bias is a problem caused by the way Medicaid pays for LTSS. Medicaid pays for LTSS from institutions as a mandatory service. But it pays for HCBS as an optional one. This means Medicaid makes it much harder to get supports as HCBS.



Long-Term Support Services (LTSS)

Long-Term Support Services are services that can help people with disabilities do the things we need to do every day. Some types of long-term support services are job coaches or in-home helpers. Long-term support services are sometimes called LTSS for short.



Mandatory services

Mandatory services are services that the law that made Medicaid says Medicaid has to pay for.



Optional services

Optional services are services that the law says Medicaid can pay for, but doesn't have to.

3. Supports in the Community



A lot of people with disabilities need help with things we need to do every day.



There are services that can help people with disabilities with these things.



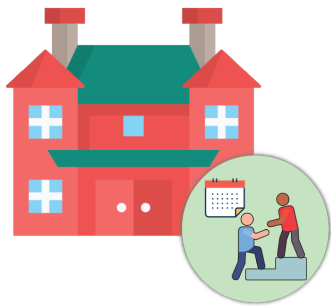
These services are called **long-term support services**, or **LTSS**.



Some types of LTSS are job coaches or in-home helpers.



There are a lot of ways to get LTSS.



Some people get LTSS in institutions.



Institutions are places where lots of people live.



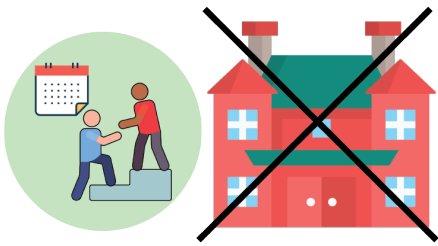
People in institutions live separate from their communities.



They don't have much control over where they can go and what they can do.



Institutions are bad for us.



The law says we have the right to get LTSS without being in an institution.



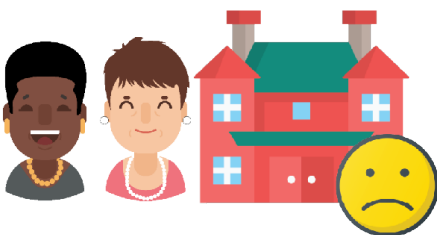
We don't need to be separated from our communities.



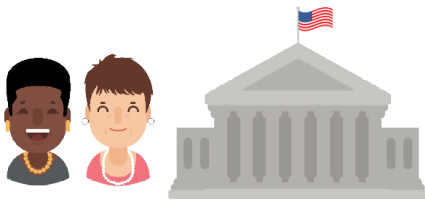
This was decided in a court case called Olmstead v L.C.



This court case was brought by two women, Louise Curtis and Elaine Wilson.



These women were being held in institutions even though they could live in their communities.



They sued the state of Georgia for keeping them in institutions.

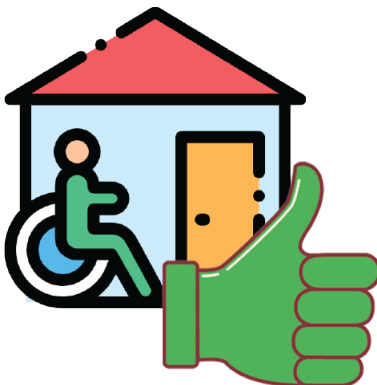


The Supreme Court said that the law gives us all the right to get support and live in our communities.

HCBS and Institutional Bias



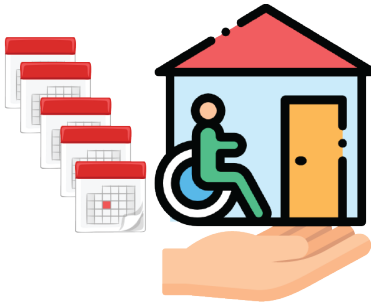
Home and Community Based Services, or HCBS for short, are a form of LTSS where people get support in the community.



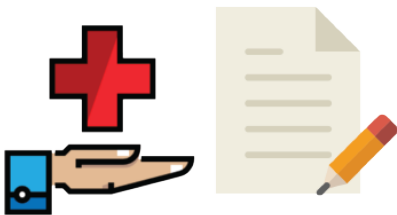
A lot of people want HCBS.



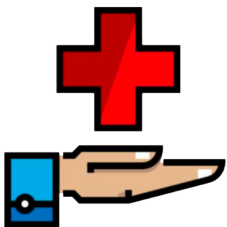
But it is very hard to get HCBS.



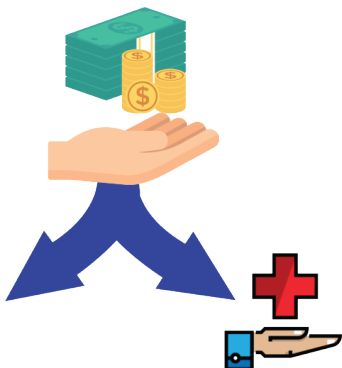
A lot of people wait a very long time to try to get it.



This is because of how Medicaid is designed.

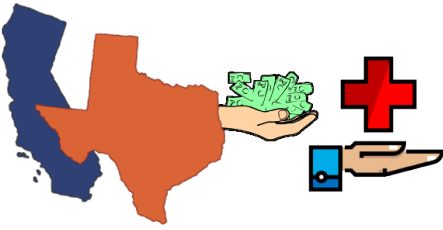


Medicaid is a program that helps people pay for health care.

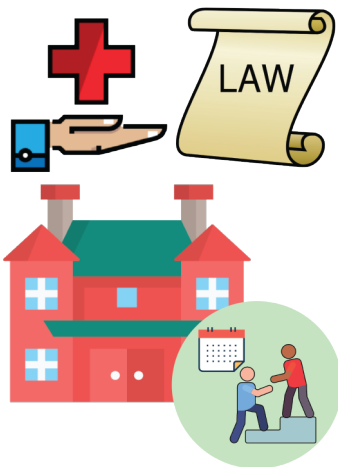


Medicaid is one of the only ways to pay for HCBS.

Medicaid is provided by the states.



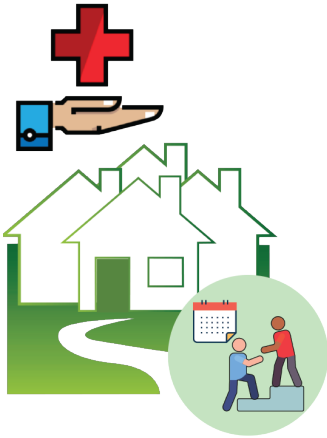
The states run Medicaid according to laws set by the federal government.



The law that made Medicaid says Medicaid has to let people get LTSS in institutions.



This is called a **mandatory** service.



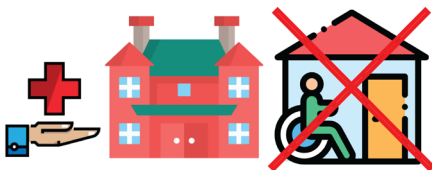
But it only says that Medicaid **can** let people get LTSS in their communities.



It isn't required.



These services are **optional**.



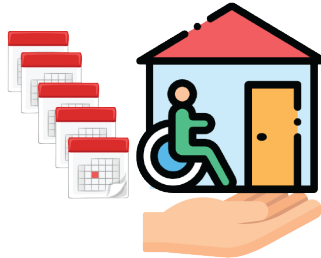
This is called Medicaid's **institutional bias**.



Many states do provide some money to pay for HCBS.



But because of institutional bias, most states don't provide nearly enough money.



This means people have to wait a long time for HCBS.



It means that many people have a lot of trouble getting HCBS.



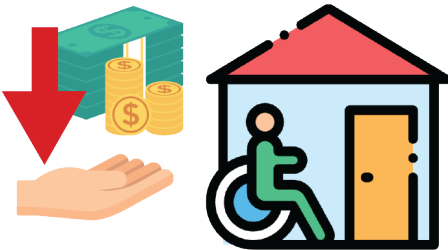
Not everyone has the same amount of trouble getting HCBS.



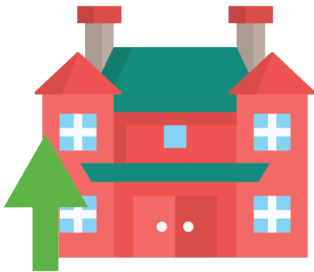
People of color have a harder time getting HCBS than white people do.



People of color get HCBS less often than white people.



Less money gets spent providing HCBS to people of color.



People of color are more likely to be in institutions.



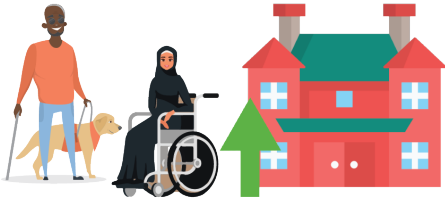
States with a lot of people of color living in them tend to have more institutions.



These states provide less HCBS.



This hurts people of color.

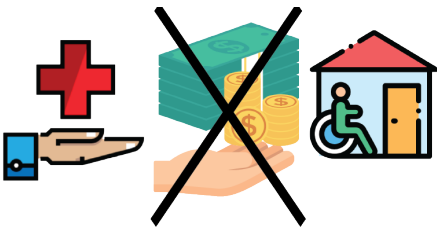


More people of color with disabilities are in institutions.

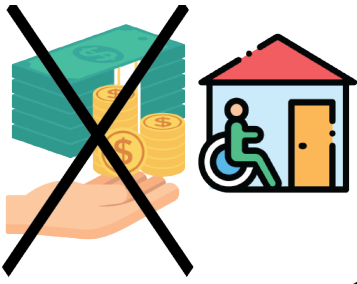


Institutions with more people of color usually are worse at keeping the people in them safe.

HCBS Workers and Racial Inequality



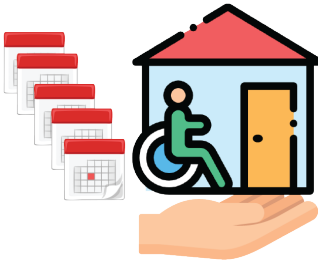
Most HCBS does not get paid for by Medicaid.



It doesn't get paid for at all.



Most HCBS is provided by family members and friends who do not get paid.



This is because there is a long wait for Medicaid to pay for HCBS in most places.



And, it is hard to get Medicaid.



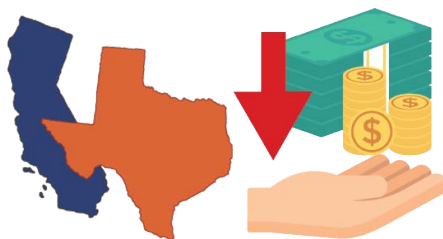
People of color are less likely to have Medicaid HCBS because of the long waits.



Some states with a lot of people of color make it harder to get Medicaid.



This makes it harder to get HCBS.



A lot of these states also spend a lot less money on HCBS.



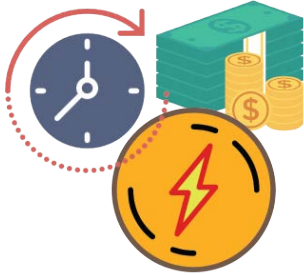
People of color get less HCBS funding when they do get it.



This means people of color have to depend even more on unpaid support.



Unpaid support is still work.



Even though it is not paid, it takes time, energy and money to do.



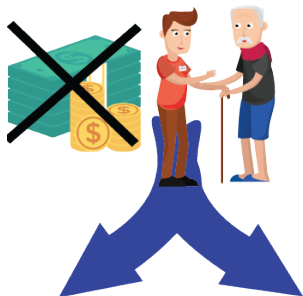
People who do unpaid support work often cannot do as much paid work.



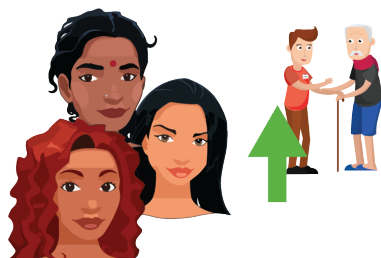
This is because they are doing a lot of unpaid work already.



They sometimes cannot work for pay at all.



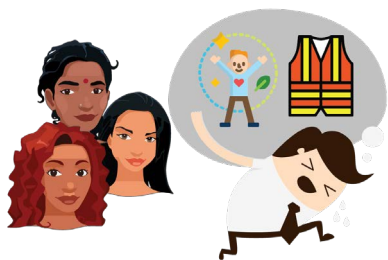
Some of them are doing unpaid support work for more than one person.



Women of color are more likely to be doing unpaid support work for more people.



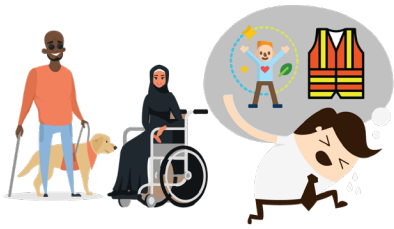
People who do unpaid support work don't have as much money.



This makes it hard for them to stay safe and healthy.



This also causes problems for people with disabilities who use unpaid support.



It makes it harder for them to stay safe and healthy too.



People with disabilities who use unpaid HCBS usually get it from friends or family.



We might live with the person who does unpaid HCBS work for us.



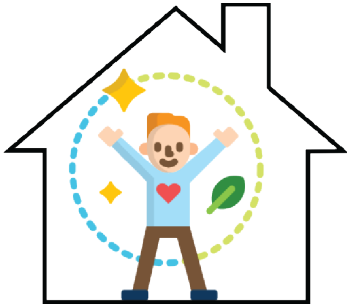
If the person who does unpaid HCBS can't afford to stay safe and healthy it hurts disabled people.



It makes it harder for people doing unpaid HCBS to do it well.



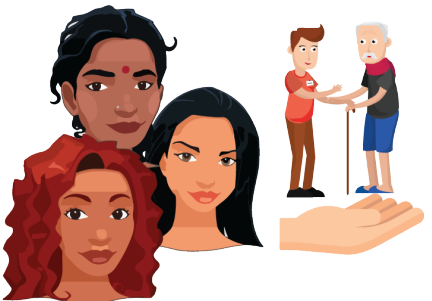
We need our friends and family to also be healthy.



We need the people we live with to also be healthy.



When they're not healthy it hurts us too.



Women of color are more likely to be support workers.



This is true for unpaid support workers.



This is also true for support workers who get paid for their work.



Support workers who are paid usually aren't paid enough.



1 out of every 8 support workers do not have enough money to live and stay healthy.



Three quarters of support workers don't earn enough money to pay for their needs.



The fact that support workers don't get paid enough is a problem that unfairly hurts people of color.



This is on purpose.



It's because of racism.



When the government first passed laws to make sure workers were safe and paid fairly, they left out some types of work.



One type of work that was left out was **“domestic work”**.



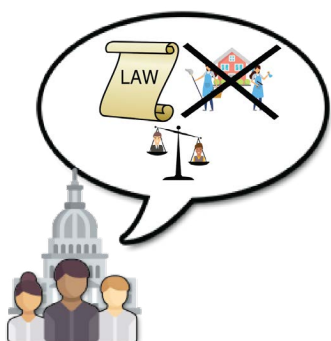
Domestic work includes HCBS and other jobs that are usually done in the home.



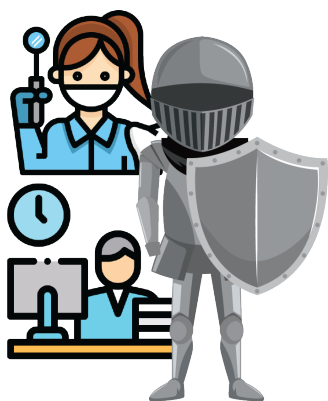
These types of work were often done by people of color.



These jobs were left out of these protections because they were done by people of color.



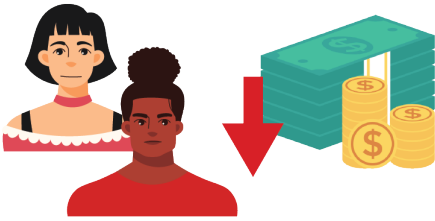
Many lawmakers said so at the time.



These jobs were never protected like other jobs.



Because of this, they never paid well.



This made it harder for people of color to make much money.



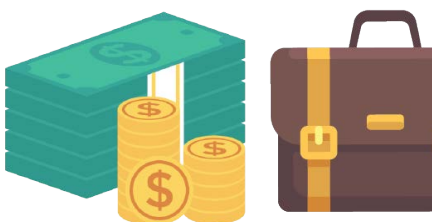
It meant people of color had less money to spend in their communities.



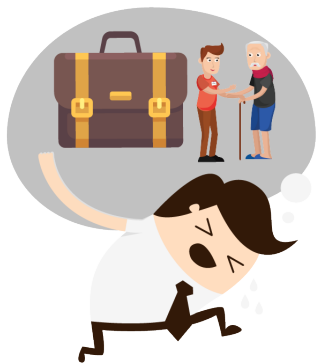
It also meant that not many people wanted to work in HCBS.



It did not pay well.



People did not get paid for all the work they did.



It was hard to keep HCBS jobs.



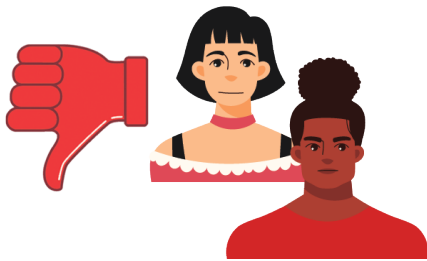
It was a lot easier to be fired.



It was hard to afford to do it for long.



It was hard to take breaks when support workers needed to.



These are problems for support workers and are a problem for communities of color.



They are also a problem for people with disabilities.



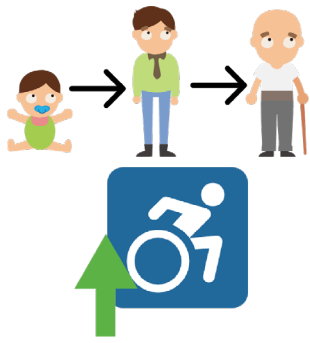
People with disabilities need HCBS.



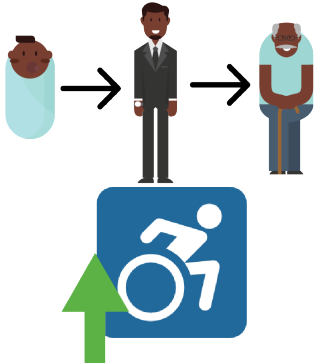
The fact that support worker jobs are often not good means that not enough people are support workers.



This makes it harder for people with disabilities to get support.



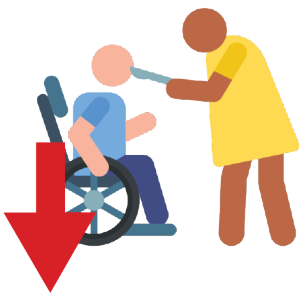
A lot of people become disabled as they get older.



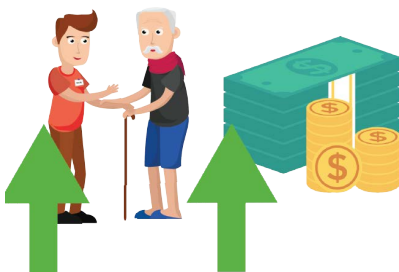
People of color are more likely to become disabled as they get older.



As more people all over the country become older, we need more support workers



But there aren't enough support workers now.

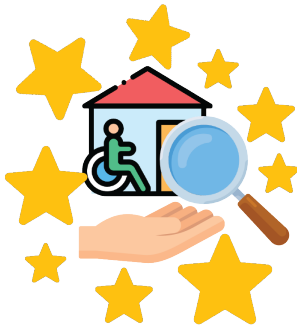


People want support workers to be better and pay better.



It is important that we make sure there are more people who want to be support workers.

What don't we know?



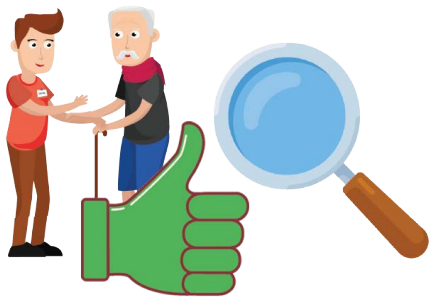
It is important to know who is getting HCBS.



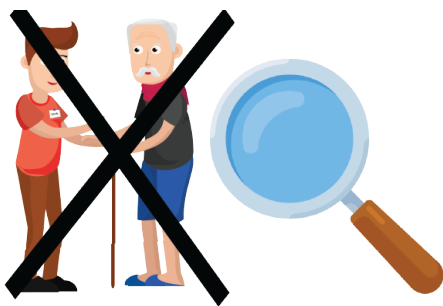
We need to know what their HCBS is like.



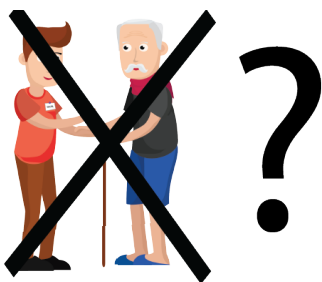
We need to know how to make HCBS better.



We need to make sure everyone is getting the support they need.



We need to know who isn't getting support.



We need to know why.



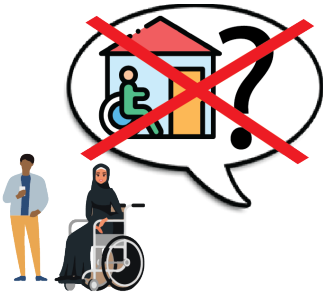
A lot of the time we don't know enough.



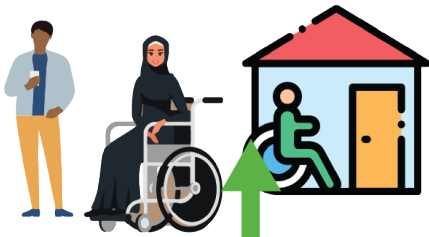
We know the most about older adults who use HCBS.



But we don't know as much about younger people.



People don't ask a lot about how younger people who need HCBS are doing.



A lot of people who use HCBS are younger.



We need to know more about them.



We also need to know more about support workers.



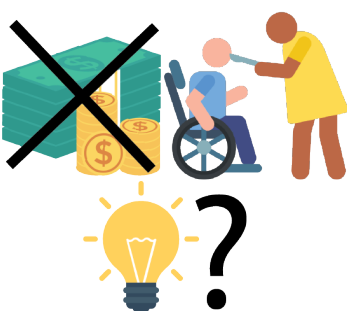
We do know a lot about people who are paid for HCBS work.



But most of the people who do HCBS work don't get paid.



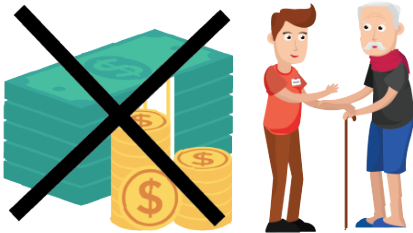
They are friends or family members.



We don't know as much about them.



That's a problem.



Most people who need HCBS don't get paid support.



Their support workers aren't paid.



They are friends or family members.



We need to understand how most people with disabilities get support.



And one thing we do know is that this affects people of color with disabilities most.



People of color who use HCBS are often younger.



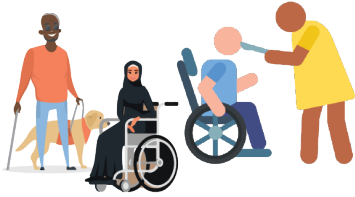
People of color who do unpaid HCBS often support younger people.



People of color who do unpaid HCBS usually support more people.



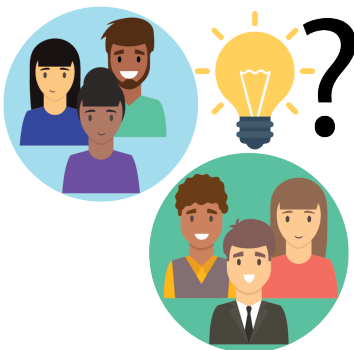
The groups we need to know more about include more people of color.



We need to know more about them.



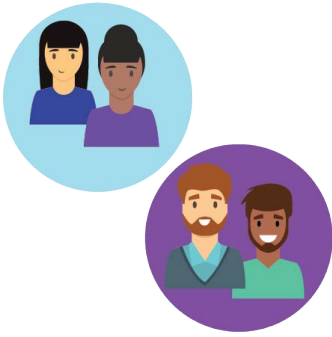
If we don't it is harder to help people of color with disabilities.



We also don't know a lot about how different communities use HCBS.



The information we have isn't specific enough.



This is because we often define communities in ways that aren't specific enough.



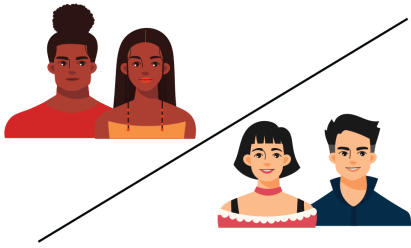
We use categories that put groups that are different together.



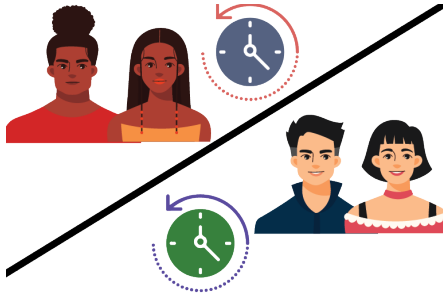
But sometimes these groups aren't the same.



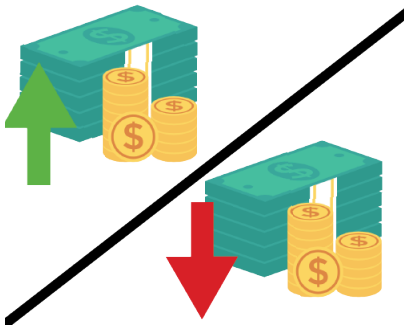
For example, Asian-Americans and Pacific Islanders are often grouped together as one group.



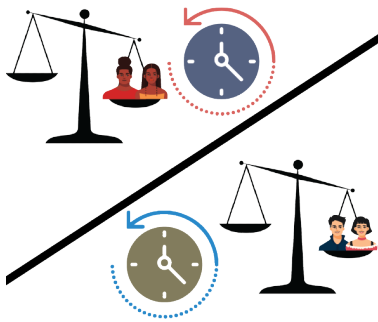
But a lot of different groups are called Asian-American and Pacific Islanders.



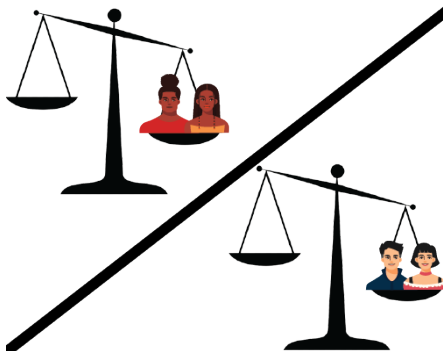
They have different histories.



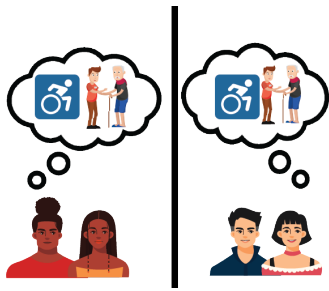
Different Asian-American and Pacific Islander groups may have more or less money than others.



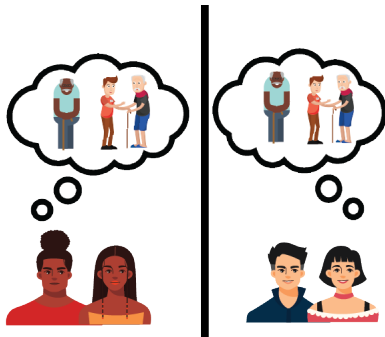
They may have experienced racism differently.



They might still experience racism differently.



They may have different ideas about how people with disabilities should get support.



They may have different ideas about how older people should get support.



By looking at Asian-Americans and Pacific Islanders as a single group we won't see that.



We need to be more specific.



We need to know what causes inequality.



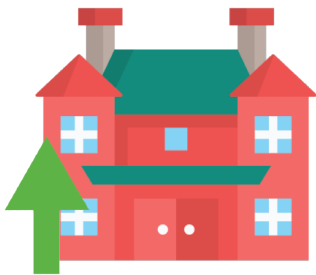
We know that there are sometimes big inequalities between different races.



But it's hard to know what causes them.



We know that people of color are less likely to get HCBS.



They are more likely to be in institutions.



We know that when people of color get HCBS less money is spent on them.



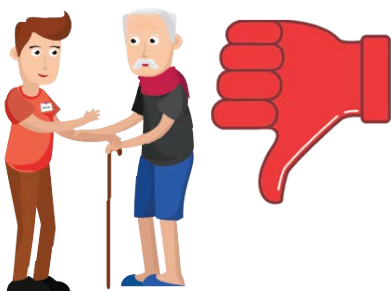
We know that people of color who get HCBS have worse health than white people.



But there are different reasons why this could be true.



People of color who get HCBS get less money spent on them.



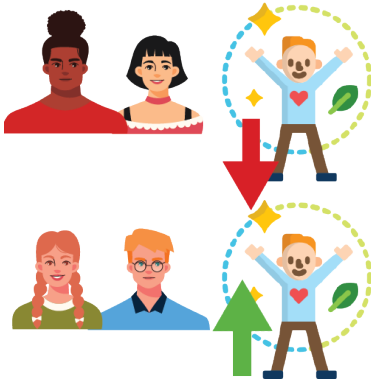
So it could be that the support they get isn't as good.



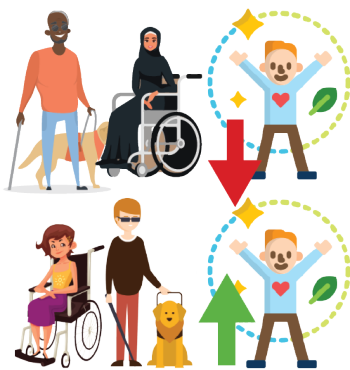
This could make them get sicker more easily.



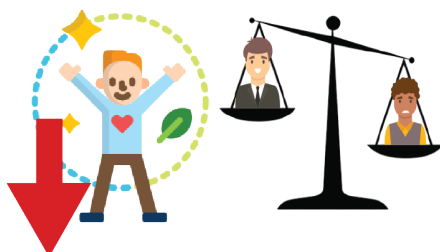
But it's also possible that people of color with disabilities had worse health before getting HCBS.



People of color often have worse health than white people.



People of color who get HCBS could also have worse health than other people who get HCBS.



They have worse health because of racism.



People of color with disabilities experience racism too.



They can even have worse effects from racism.



It is important to figure out what's going on.



We can't fix a problem until we know why it is happening.



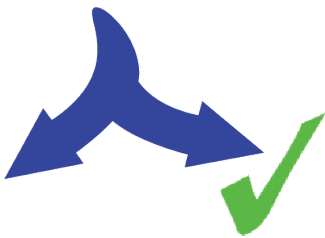
We know that HCBS isn't working as well for people of color.



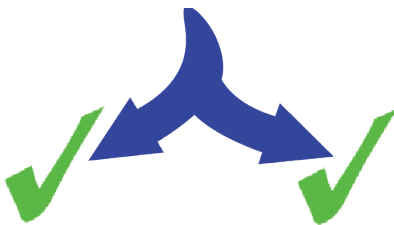
That could be because HCBS needs to be done better to help people of color.



It could be because people of color have more health problems already.



One answer might be true.



Both answers might be true.



It is important to know.



Knowing this can help us figure out the best ways to improve HCBS.



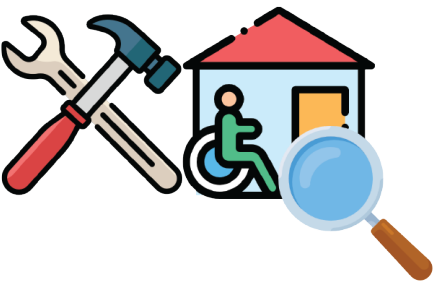
It can help us make sure HCBS works better for people of color.

What can we do?

Get better information



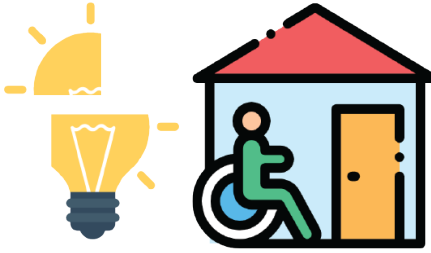
We need to make HCBS work better.



To do that, we need to know how to make it work better.



Right now, we don't have all the right information.



We are missing information.



Sometimes the information we do have is not very useful.



The government can collect this information.



But it doesn't do a good job of getting it.



It doesn't get all the information we need.



It doesn't get it in helpful ways.



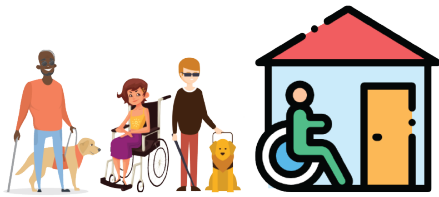
We need to know about everyone who uses HCBS.



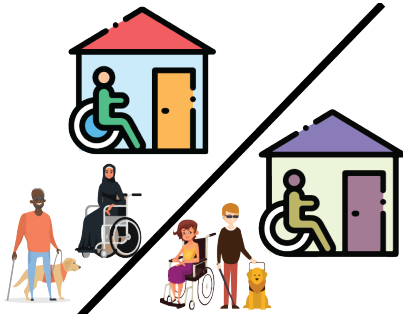
We need to know about everyone who does HCBS work.



We need to know more about people who are younger and use HCBS.



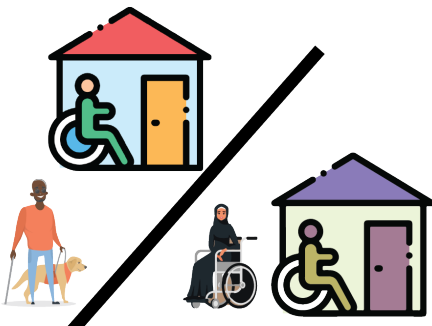
We need to know about the races of people who use HCBS.



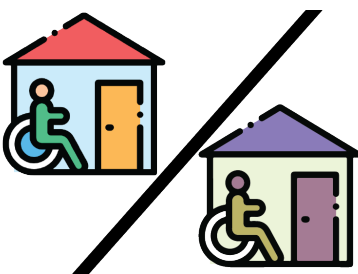
We need to know when people with different races use HCBS differently.



We also need to ask about different disabilities.



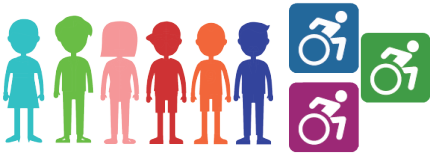
We need to know if people with different disabilities use HCBS differently.



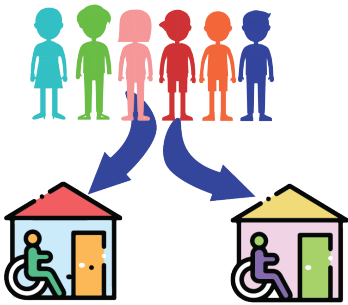
Other things can also cause differences.



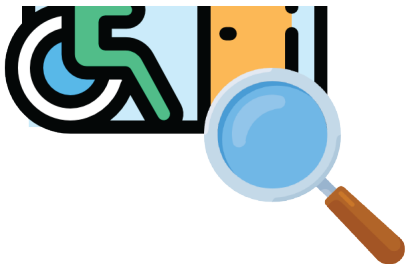
We know that HCBS workers have different experiences based on their gender.



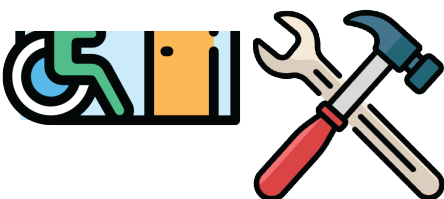
People with different genders also experience some disabilities differently too.



We should know if this changes how people use HCBS.



We need to be specific.



We should make sure we get information specifically enough to be useful.



If autistic Black people have a problem with HCBS we need to know this.



We might not know this if we only look at all autistic people.



We might not know it if only we look at all Black people with any disability.



If we don't look specifically we might not notice a problem at all.

Some people have more than one kind of disability.

We should also look at how this affects how they use HCBS.



We need to compare different groups to understand these problems.



We need to know if the groups we use are too big to spot the real problems.

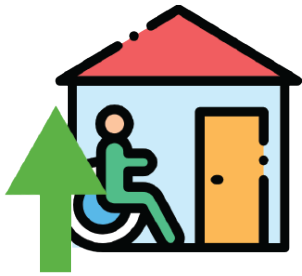
Make Sure HCBS Has Enough Money And Helps Everyone Who Needs It



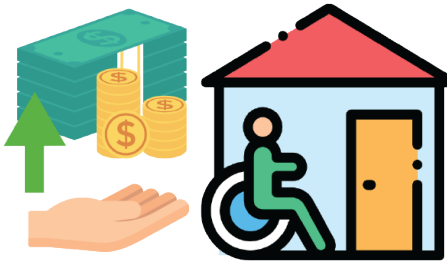
We have a right to get support in our communities.



But that right has not been supported.



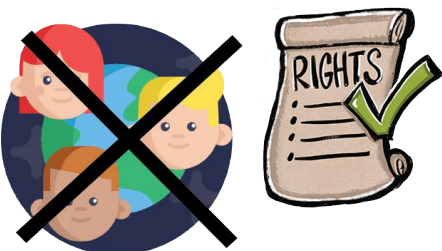
To support it we need to make sure people can get HCBS.



This means we need more money for HCBS.



More money means that more people can get HCBS.



Otherwise it is a right that only some people have.



Right now a lot of people who need HCBS can't get it.



This is because there isn't enough money for it.



A lot of people who do need support are forced to be in institutions.



Making sure HCBS has enough money will improve inequalities.



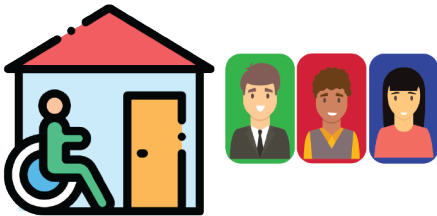
It will help fix unfair differences in who can stay in their communities.



If everyone can get all the supports they need in the community, then we can close institutions.



At the same time we need to make sure that support in the community is helping everyone.



There are also racial disparities between people who do receive HCBS.



Black people who use LTSS are more likely to get sick than white people who use LTSS.



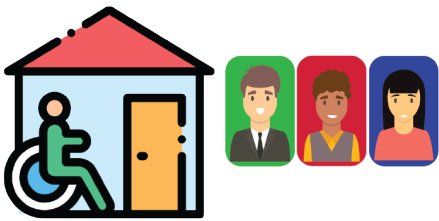
They are more likely to need to go to the hospital.



This is true when they are institutions.



This is also true when they get support in the community.



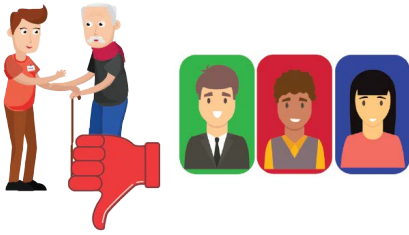
The difference between Black and white people who receive HCBS is even bigger.



Black people get less support than white people.



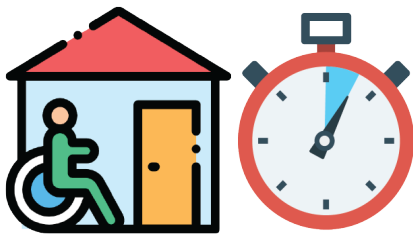
The support Black people get isn't as good as the support white people get.



This is probably part of the reason for this difference.



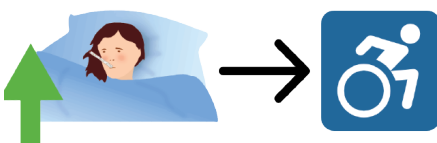
But other things also put Black people who need HCBS at risk.



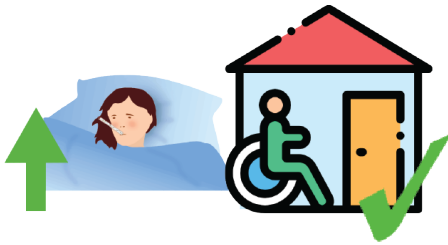
Black people are more likely to need HCBS younger.



This is also because they have more risk of getting sick.



Getting sick can make them become disabled.



This also means they can continue to be at risk of getting sick with HCBS.



We need to know what causes these risks.



We need to know what we can do to make them better.



This means fixing health inequity.

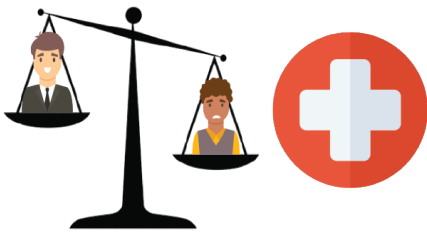


Health inequity is when some groups of people are less healthy than others because of unfair differences in where and how they live.

Fixing health inequity means doing something about:



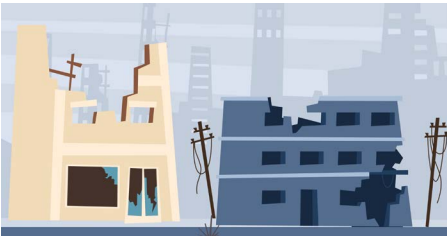
- Access to doctors and nurses.



- Racism in systems which makes it harder to get support.



- People not having a lot of money and the effect this has on staying healthy.



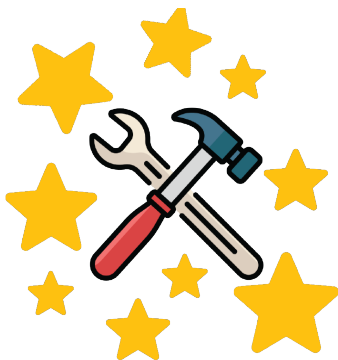
- Communities not having a lot of money and the effect this has on what communities have in them.



We need to do something about all of these things.



If we do, we can make sure we are supported, safe and healthy in our communities.



Improving health inequity is as important as fixing unfair differences in HCBS itself.

Improve pay for HCBS workers



HCBS workers need better pay.



They need better work conditions.



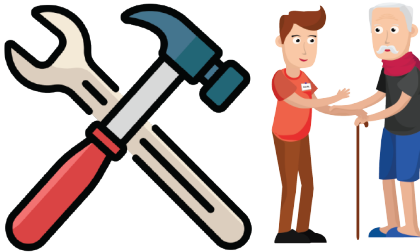
More support workers deserve to be paid for their work.



This would make HCBS work more fair for workers.



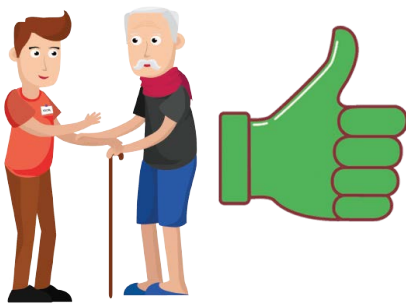
This can fix a source of racist inequality.



It also would make these supports work better for people with disabilities.



This would help to fix an inequality for people of color with disabilities.



It would mean that they would get better care than they do now.



More people could do this work.



This would help make sure there are enough HCBS for everyone who needs it.



People doing unpaid HCBS work should also be able to get paid for that work.



This can also help people with disabilities.



People with disabilities' friends and family are only able to provide support if they are safe and healthy.



If they don't have enough money, it can be very hard to stay safe and healthy.



This makes it harder for these people to provide support.



This hurts people with disabilities.



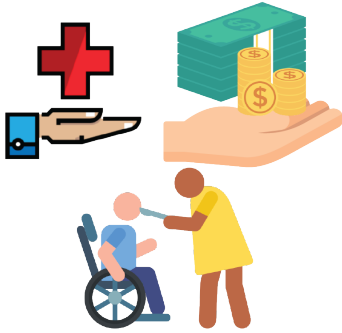
Another important way to improve HCBS jobs is to pay workers more.



When we make new laws to pay people more, we need to think about HCBS in particular.



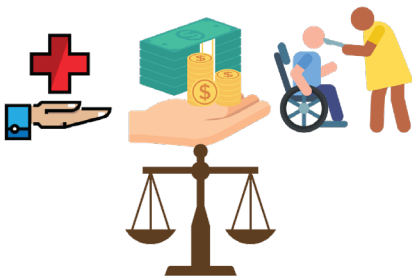
We need to make sure that we think about how they're paid.



Many HCBS workers are paid by Medicaid.



This means that when we make sure everyone is paid a fair wage we need to remember this.



We need to make sure that Medicaid pays HCBS workers a fair amount.