



Easy Read Edition

A Self-Advocate's Guide to **Managed Long-Term Services and Supports**

Part 3: Managed LTSS

Words to Know in Part 3



advisory groups

Groups that give advice to states about programs the state runs.



care coordination

When health care providers work together to help someone get good care.



Centers for Independent Living (CIL)

Places that help people with disabilities make our own choices about our lives.

There is usually a CIL in big cities.

Sometimes there will be one CIL that helps a group of small cities.



Developmental Disabilities (DD) Council

Groups that work to help people with developmental disabilities. They figure out problems that the state can fix to help us. Each state has a DD Council.



fee-for-service

When a state pays a health care provider every time someone on Medicaid gets health care.



health care providers

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



home and community-based services (HCBS)

What it is called when people get LTSS in their community.



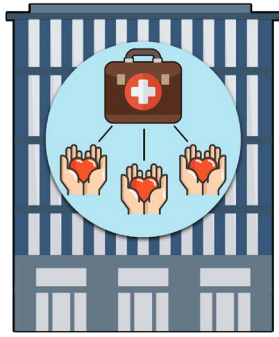
long-term services and supports (LTSS)

Services that help disabled people live our everyday lives. Some kinds of LTSS are job coaches or in-home helpers.



managed care

When a state pays an insurance company to run their Medicaid program. Then, the insurance company pays for the health care for people on Medicaid.



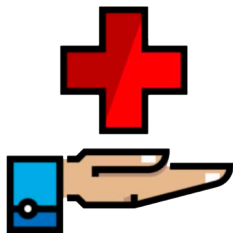
Managed Care Organization (MCO)

Private insurance companies that work with the state to run the state's Medicaid program.



managed long-term services and supports (MLTSS)

When a health insurance company runs a Medicaid LTSS program.



Medicaid

A health care program in the United States. It gives health care to people who can't pay for health insurance.



Protection and Advocacy agencies (P&A)

Places that help people with disabilities fight for our rights. There is a P&A in every state.



risk

The chance that someone could lose money.

3. Managed LTSS

What is LTSS?



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



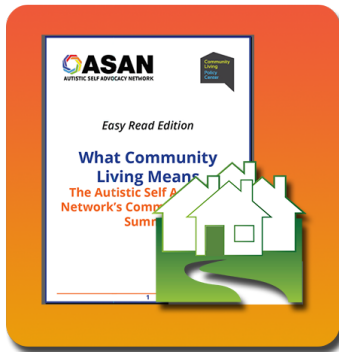
Some people get LTSS in institutions.
Other people get LTSS in their community.



Getting LTSS in the community is also called **home and community-based services (HCBS)**.



We want to make sure everyone can get LTSS in their communities.



You can read more about this in our [Community Living Toolkit](#).

What are Managed LTSS?



Many state Medicaid programs already use managed care.



But they only use it for some kinds of health care.



They use managed care for health care that happens over a short time.

For example:



- Going to a doctor to get medicine when you get sick.



- Getting surgery.



- Staying in the hospital for a couple of days.



But managed care programs can also get used for LTSS.



This is called **Managed LTSS**.



Some people call this “MLTSS” for short.



Remember, switching from fee-for-service to managed care takes a long time.



It can take years.



Switching from fee-for-service LTSS to Managed LTSS also takes a long time.



States have to find an MCO to run the Managed LTSS program.



States have to figure out how much to pay an MCO for each person getting LTSS.



States have to figure out the right questions to ask about LTSS.

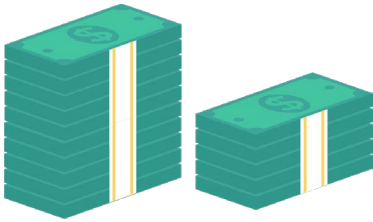


They need to make sure MCOs give people good LTSS.

Should Managed LTSS pay for institutions?



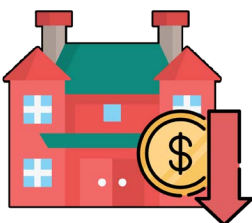
Switching to Managed LTSS can help more people live in the community.



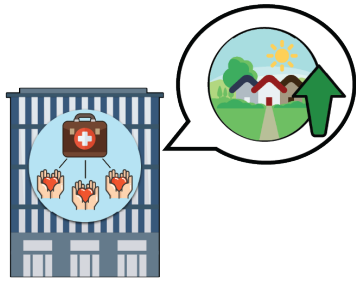
That's because states can pay different amounts of money for different kinds of LTSS.



States can give MCOs more money for people getting LTSS in their community.



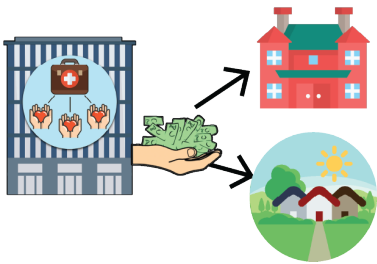
States can give MCOs less money for people getting LTSS in an institution.



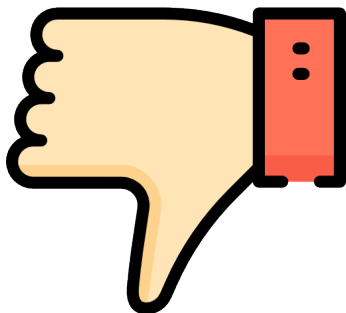
Then, MCOs will want more people to get LTSS in their communities.



This can help people stay out and move out of institutions!



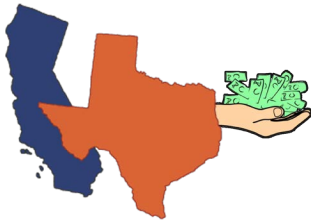
But it's important that MCOs pay for LTSS in the community and institutions.



It would be bad if MCOs only paid for LTSS in the community. Here's why:



States have to pay for people to get LTSS in institutions. That is the law.



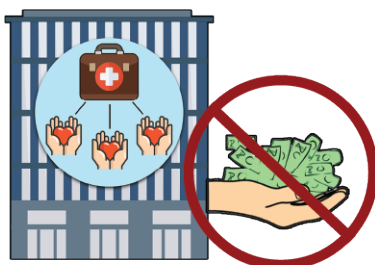
If MCOs don't have to pay for institutions, the state has to do it instead.



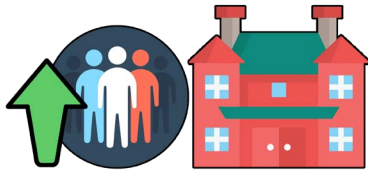
MCOs might try to save money.



They might say lots of people who get LTSS need to be in institutions.



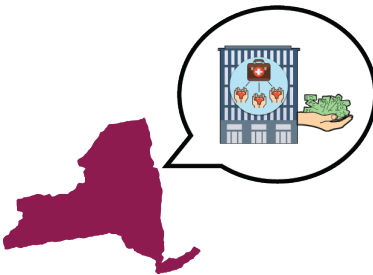
Then, MCOs won't have to pay for those people at all.



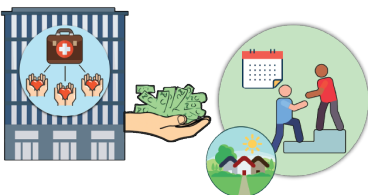
But more people would end up in institutions. That is bad.



States can keep that from happening!



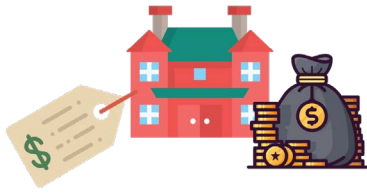
States can make MCOs pay for LTSS no matter what.



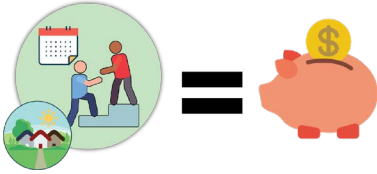
That way, MCOs would have to pay for LTSS in the community.



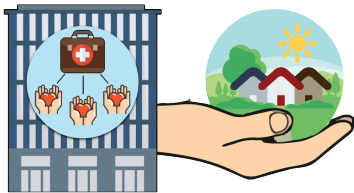
MCOs would have to pay for LTSS in institutions, too.



But institutions cost a lot of money.



MCOs can save money by giving people LTSS in the community.



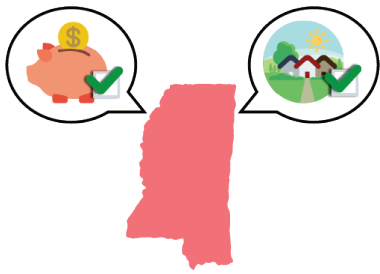
So they will try to give people LTSS in the community instead.



MCOs want to save money.



People with disabilities want to get LTSS in the community.



States can make sure both these things happen.

What are some good things about Managed LTSS?



There are lots of ways that Managed LTSS can help people who get LTSS!



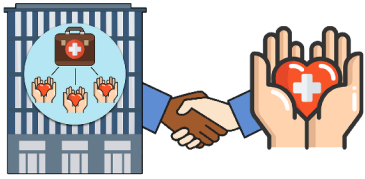
MCOs have to make sure people on Medicaid get what they need.



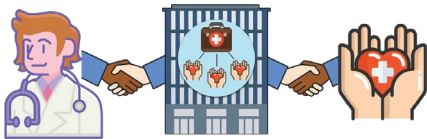
MCOs also want to save money.



So MCOs look for smart ways to help people while saving money.



One way MCOs do this is by working with **health care providers.**



They can work with doctors and LTSS providers at the same time.



They make sure doctors and LTSS providers talk with each other.



This makes sure that health care providers don't waste time or money.



It also helps health care providers give better health care.



Everyone works together.



This is called **care coordination**.



Care coordination is when an MCO gets different health care providers together.



The MCO makes sure they talk to each other about one person's care.

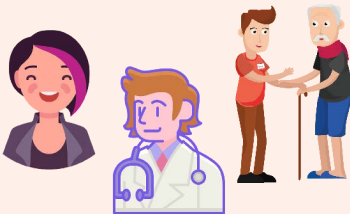
For example:



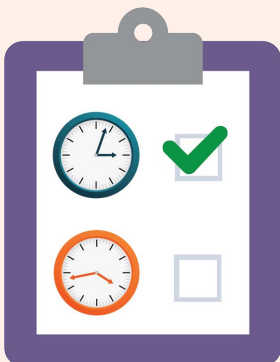
Sydney gets LTSS in their own apartment.
They have an in-home helper.



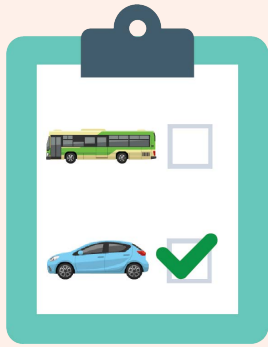
Sydney needs to go to the doctor.



Sydney's MCO helps Sydney, their helper,
and their doctor work together.



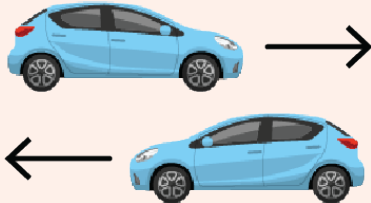
Everyone works out the best time for
Sydney to go to the doctor.



Then, they work out how Sydney will get to the doctor.



Sydney's helper makes sure Sydney is ready to go to the doctor.



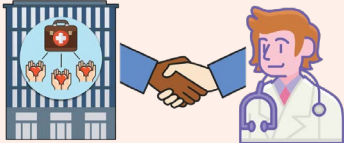
The MCO helps Sydney get a ride to and from the doctor.



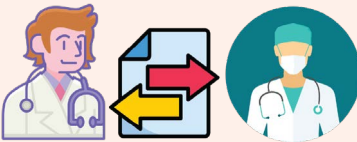
The doctor takes notes about what Sydney needs.



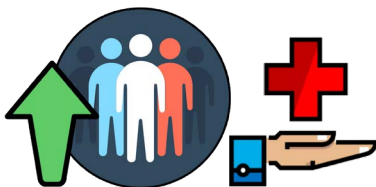
Later, Sydney needs to see a surgeon.



Sydney's MCO works with Sydney's doctor.



They make sure Sydney's doctor shares his notes with the surgeon.



When MCOs save money, that money can help more people get Medicaid.



It can help people on Medicaid get more health care.



It can help more people get LTSS in the community.

For example:



Some people on Medicaid get LTSS in institutions.



They want to get LTSS in the community instead.



The MCO saves money.



The MCO uses the extra money to move people out of institutions.



Asking the right questions about LTSS can help people, too.



States can ask questions about getting LTSS in the community.



They can check that MCOs do a good job giving LTSS in the community.

For example:



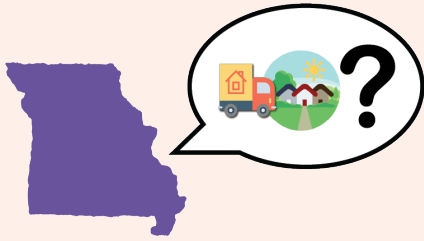
People who get LTSS want to live in the community.



A state wants to make sure everyone can live in their communities.



They want to help more people move out of institutions.



The state asks questions to see if their MCO helps people move into the community.

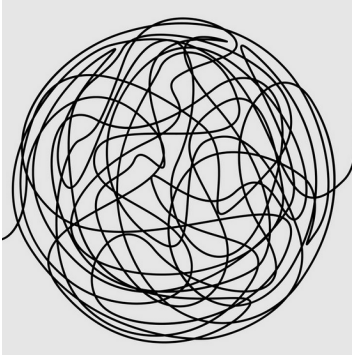


If the MCO helps people move into the community, they get more money.

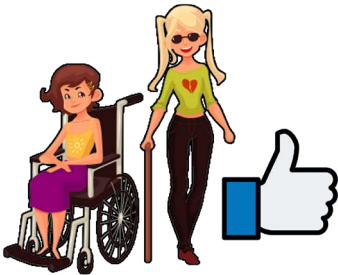


So the MCO helps a lot of people move into the community.

What are some things to watch out for as states switch to Managed LTSS?



Making big changes to health care is very hard.



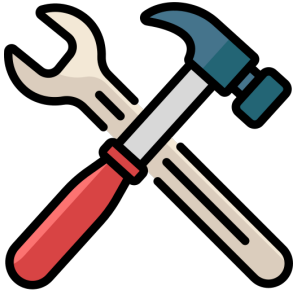
States have to make sure Managed LTSS works for people with disabilities.



There are some things they need to be careful about.

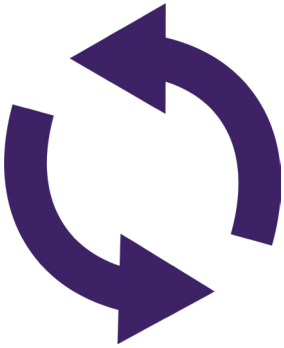


Here are some problems states might have when they switch to Managed LTSS.

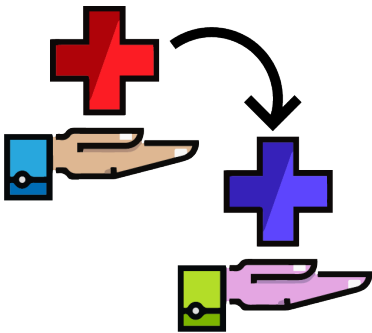


But states can help fix these problems before they start!

Problem 1: Losing Health Care



MCOs can change how a state's Medicaid program works.



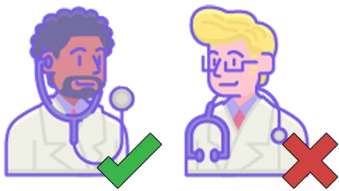
The program may not be exactly how it was before.



MCOs could decide not to pay for certain kinds of health care.



For example, they could stop paying for help while someone sleeps.



MCOs could decide to change what providers people can use.



That means people could lose services they need when Medicaid changes.

For example:



Chanda needs help all of the time.



She needs help even when she is sleeping.



She gets help from an in-home helper.



She has always used the same helper.



Chanda's state switches to Managed LTSS.



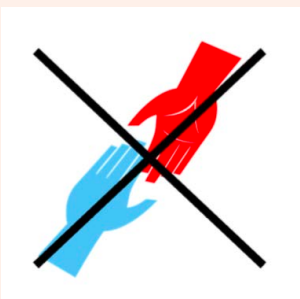
The MCO tells Chanda she can't get help while she sleeps anymore.



They also say she needs to use a different helper.



This is very scary for Chanda.



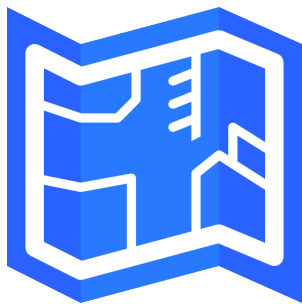
She can't get the help she needs.



And she has to get help from someone she doesn't know.



States can fix this problem when they make their managed care programs.



States can make their plans talk about this.



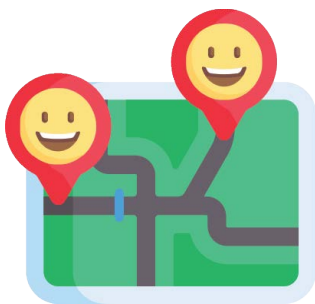
They can make MCOs cover the same services the Medicaid program had before.



States can make sure everyone can keep the same providers.



States can make sure the MCO works with a lot of different providers.



That way, people have what they need wherever they live.

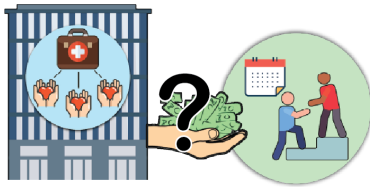


States can help plan the change to managed care.



They can make sure nobody loses their health care.

Problem 2: Paying For Managed LTSS

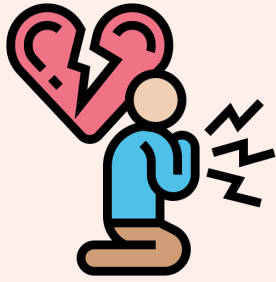


We also need to think about how MCOs will pay for LTSS.



Paying for LTSS is different than paying for doctors.

For example:



Ned gets Medicaid. He had a heart attack.



Ned's MCO paid for his heart surgery.



They paid for him to stay in the hospital.



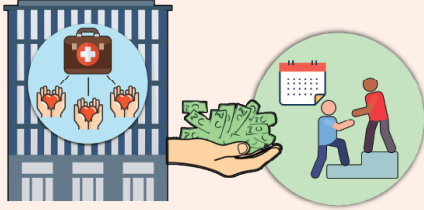
Ned's MCO only had to pay for them once.



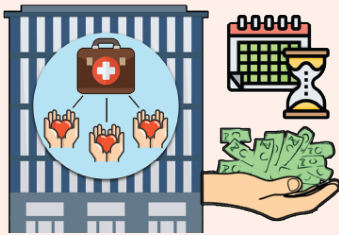
Ned needs LTSS after his heart attack.



He will probably need LTSS for the rest of his life.



Ned's MCO pays for Ned's LTSS.



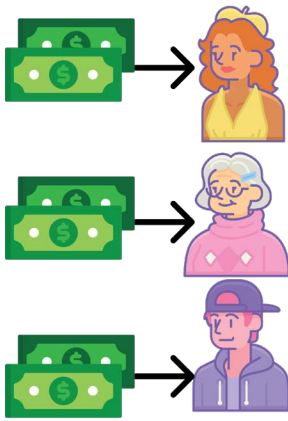
Ned's MCO has to keep paying for LTSS for the rest of Ned's life.



MCOs have to pay for LTSS for a long time.



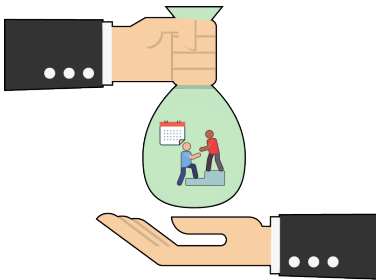
They might worry they will lose money if they pay for LTSS.



States can pay MCOs enough money for everyone who needs LTSS.

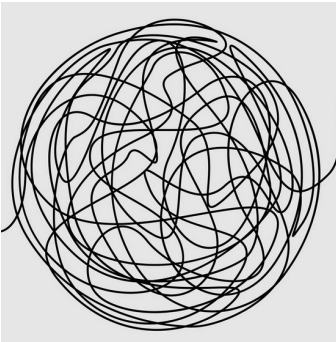


That way, MCOs won't worry about losing money.

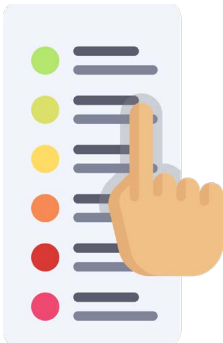


They will want to give people LTSS.

Problem 3: Asking the Right Questions



Asking the right questions about LTSS can be tricky.



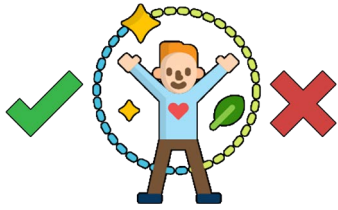
Right now, we don't have one good list of questions about LTSS.



It is harder to come up with questions about LTSS.

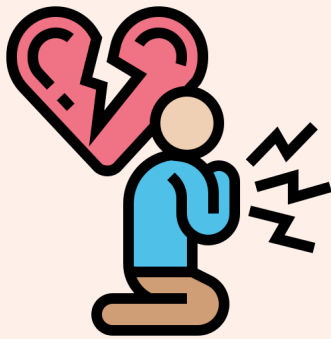


LTSS are much different than other kinds of health care.



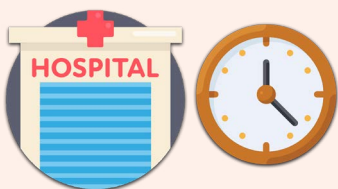
Most other kinds of health care only think about if people are healthy or not.

For example:



Ned had a heart attack.

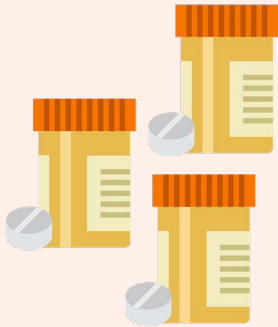
There are lots of questions the state can ask to check how Ned is doing:



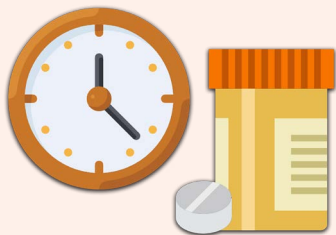
They can ask how long Ned needed to stay in the hospital.



They can ask how long Ned stays alive after the heart attack.



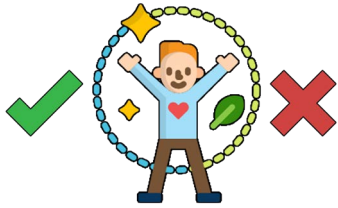
They can ask how much medicine Ned needs to help his heart.



They can ask how long Ned needs medicine to help his heart.



But LTSS isn't just about health.



People need LTSS whether they are healthy or not.



And, the things we need to check are different.

We need to ask questions like:



Are people safe?



Are people in charge of their lives?



Are people happy?



Are people in the community?



States can make sure they ask the right questions about LTSS.



States can talk to people with disabilities.

They can ask good questions about our services. They can ask questions like:



Does LTSS help us achieve our goals?



Are we happy with the LTSS that we get?



Can we see all the health care providers we need to see?



How well do our health care providers work with each other?

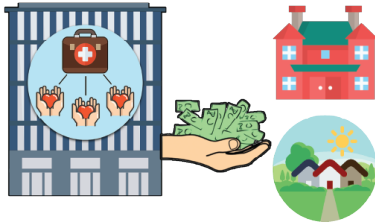


Do we get LTSS in our communities?

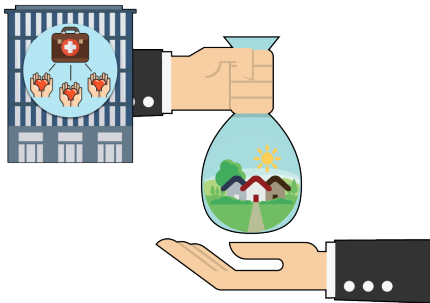


These questions can help states check if we are getting good LTSS.

Problem 4: Moving People out of Institutions



MCOs need to pay for both LTSS in the community and in institutions.



States need to make sure that MCOs make sure people get LTSS in the community.



It usually costs less money for people to get LTSS in the community.



But, moving out of institutions costs a lot of money.



MCOs might not want to pay to help us move.



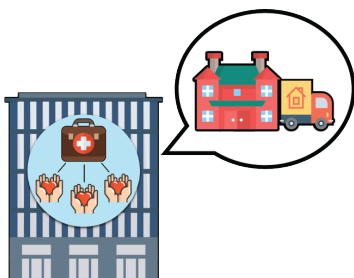
So we might end up stuck in institutions.



States can give MCOs a reason to help people move into the community.

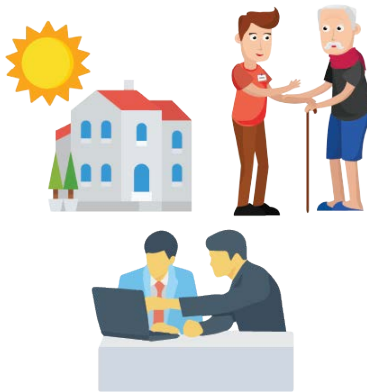


States can pay MCOs more money for moving people into the community.

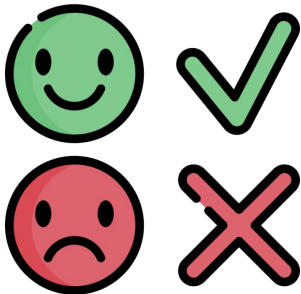


Then, MCOs will want to help get people out of institutions.

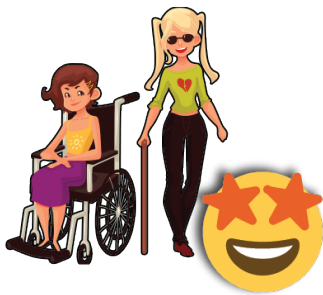
Problem 5: Getting the right services



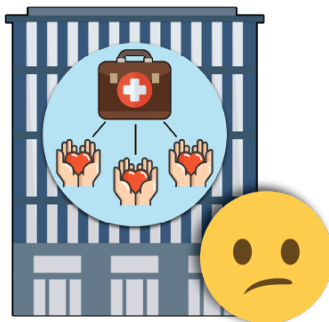
There are a lot of different kinds of LTSS for people with disabilities.



Some kinds are better than others.

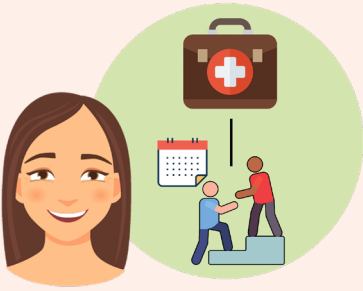


This is important to people with disabilities.



But it is not always as important to MCOs.

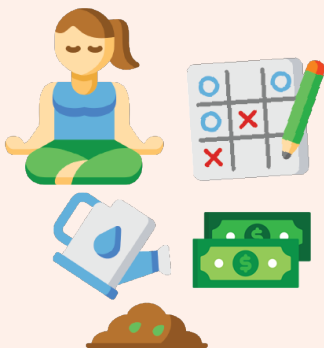
For example:



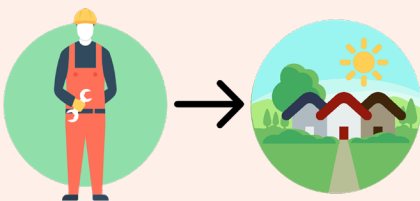
Gisele gets LTSS. Her state has Managed LTSS.



Gisele's MCO gets money to pay for Gisele to do something during the day.



The MCO gets the same amount of money no matter what Gisele does.



Gisele wants to get a job in her community.



But sending Gisele to a day program costs less money.



Gisele's MCO sends her to a day program.



Gisele's day program doesn't let Gisele go into her community.



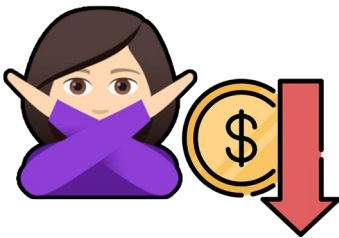
Gisele is sad that she can't get a job.



States can give MCOs a reason to give people the LTSS we want.



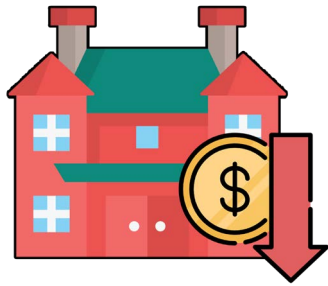
States can pay MCOs more money for LTSS that help us meet our goals.



States can pay MCOs less money for LTSS that we don't want.



States can pay MCOs more money for LTSS in the community.



They can pay MCOs less money for LTSS in institutions.

Here is a good example:



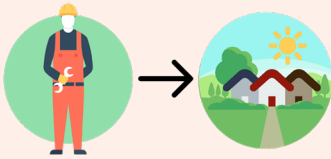
Kwame gets LTSS. His state has Managed LTSS.



Kwame's MCO gets money to pay for Kwame to do something during the day.



The MCO gets more money if Kwame is in his community during the day.



Kwame wants to get a job in his community.



Kwame's MCO gets paid more money to help Kwame get a job.



The MCO helps Kwame find a job.



They help Kwame get a helper to teach Kwame how to do the job.



Kwame gets to be with his community.



Kwame is happy that he got a job!

How can people who use LTSS help make sure Managed LTSS works for us?



People who use LTSS can help states when they switch to Managed LTSS.



People who use LTSS know best what works for us.



States don't always talk with us when they work out their managed care programs.



States may not understand what kind of LTSS we want.



They may not understand why being in our communities is important to us.



They may not know how to ask the right questions about LTSS.



That is why we need to make sure states listen to us!

Here are some ways you can help make good managed care programs in your state:

Try joining a local or state disability advocacy group.



They may know people in your state government who work on Medicaid.



You can call, email, or meet in-person with these groups.



You can let them know what you think about Managed LTSS.

Some groups you may want to reach out to are:



- Your **Center for Independent Living (CIL)**.



CILs help people with disabilities make our own choices about our lives.



They can help us get HCBS.



There is usually a CIL in big cities.
Sometimes there will be one CIL that helps a group of small cities.



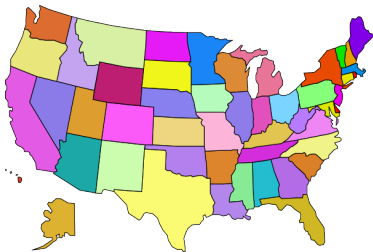
- Your **Protection and Advocacy agency (P&A)**.



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.



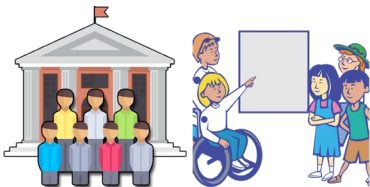
- Your state's **Developmental Disabilities (DD) Council**.



DD councils work to help people with developmental disabilities.



They figure out problems that the state can fix to help us.



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.

You can be a part of state advisory groups.



Advisory groups give advice to states as they work out managed care programs.



The groups keep meeting as the program gets going.



The state and the group look at what problems come up.



Then, they figure out ways it can be made better.

You can be a part of a focus group or town halls in your community.



You can let people know what you think about changes to Medicaid.



States may also do this online, like through a webinar.



This is good for people who can't come to in-person meetings.

Many states will make websites with information about changes to Medicaid.

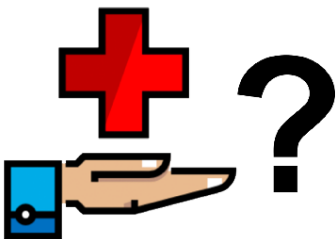


You can look at this information to learn how these changes will affect you.

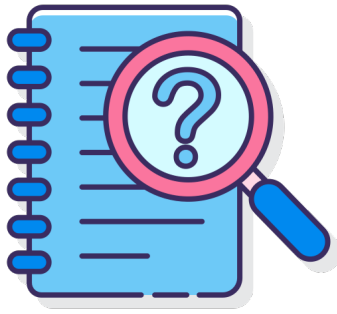
Sometimes states will put out surveys about Medicaid.



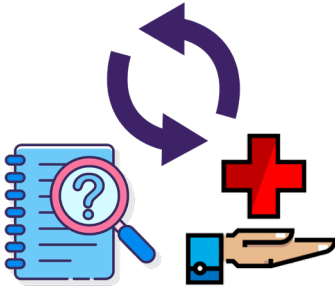
These surveys are usually online.



The surveys ask how people feel about Medicaid.



Then, the state looks at all the survey answers.



States use these answers to make changes to Medicaid.



You can answer these surveys when your state asks about managed care.



You can tell other people to answer the survey, too.



You can show your state that a lot of people care about Medicaid.



You can share your ideas about making
Managed LTSS work for us.



Nothing about us, without us!