

Anthem[®]



Plain Language Edition

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

To start

This toolkit is about **Managed Long Term Services and Supports**. We call them “**Managed LTSS**” or “**MLTSS**” for short.

This toolkit will help answer these questions:

- What is Medicaid?
- What is health insurance?
- How does Medicaid pay for health care, and how can states switch how they pay for Medicaid?
- What is managed care?
- What are long-term services and supports (LTSS)?
- What are Managed LTSS?
- What are the good things about Managed LTSS, and what are some things to watch out for about Managed LTSS?
- How can people who get LTSS help make sure that Managed LTSS works for them?

Medicaid and Managed Care

What is Medicaid?

Medicaid is a health care program in the United States. The government runs Medicaid, and every state has its own Medicaid program. You can learn more about Medicaid in our Medicaid Toolkit.

Many people with disabilities get help from Medicaid. Medicaid helps people who can't pay for health insurance get health care.

What is health insurance?

Medicaid is a kind of **health insurance**. Health insurance helps people pay for health care. People can buy health insurance for themselves, or they can get it from their job.

People pay a health insurance company some money every month. Then, the health insurance company pays for people to get health care.

There are 2 kinds of health insurance: public health insurance and private health insurance. **Public health insurance** is run by the government, while **private health insurance** is run by insurance companies. Medicaid is one kind of public health insurance.

How does Medicaid pay for health care?

Medicaid programs work with **health care providers**. Health care providers are people or places that give health care, like doctors, hospitals, or social workers. There are 2 different ways that states can pay health care providers: fee-for-service and managed care.

Way 1: Fee For Service

When someone on Medicaid needs healthcare, the state pays the health care provider.

It doesn't matter how much health care someone needs, or how many times someone needs health care. The state has to pay the health care provider every time. This process is called **fee-for-service**.

For example:

Hugo gets Medicaid, and he needs an x-ray. Hugo's state Medicaid program pays the doctor that does the x-ray. Hugo finds out from the x-ray that he needs surgery. Hugo's state Medicaid program pays the surgeon to do Hugo's surgery.

All the health care Hugo needs gets paid for by the state.

Way 2: Managed Care

The other way states can pay for Medicaid is called **managed care**, which is much different than fee-for-service. The state doesn't pay health care providers - it pays an insurance company instead. Then, the insurance company pays health care providers.

Each state's Medicaid program works with a **Managed Care Organization (MCO)**.

MCOs are insurance companies that make a deal with the state to run the state's Medicaid program. The state is still in charge of the Medicaid program, but the MCO does the work.

The state gives the MCO money for each person on Medicaid. The MCO puts all the money together, then uses that money to pay for health care.

Some people will need more health care, while other people will need less. The MCO uses all of the money put together to pay for what everyone needs. Then, the MCO pays health care providers using this money.

For example:

Yumi gets Medicaid, and her state's Medicaid program has managed care. Yumi's state works with an MCO called HealthCorp. The state pays HealthCorp some money for Yumi to get health care. Because Yumi gets Medicaid, she gets health care from HealthCorp.

Yumi needs to get an x-ray, so HealthCorp pays the doctor that does the x-ray.

Yumi finds out from the x-ray that she needs surgery, so HealthCorp pays the surgeon to do Yumi's surgery. All the health care Yumi needs gets paid for by HealthCorp.

What is Risk?

Risk is an important idea in health care. Sometimes, we think we know how much something will cost, but we aren't always right. We might have to pay more than we wanted to, and end up losing money. The chance of losing money is called **risk**. Whoever could lose money is taking the risk.

For example:

Lamar needs to go to the doctor, but he doesn't know how much the doctor will cost. Lamar thinks the doctor will cost \$50. The risk is that the doctor might cost more money. Even if the doctor costs more money, Lamar still has to pay. Lamar takes the risk.

With fee-for-service, the state takes the risk. The state has to pay for the health care for people on Medicaid, no matter how much it costs. If it costs more than they thought it would, the state will have to cover the extra costs. The state might go into debt, or it might have to spend less money on something else.

With managed care, the MCO takes the risk. The state gives MCOs a set amount of money, and that money needs to pay for all the health care for everyone on Medicaid.

If health care ends up costing more, the MCO won't get more money from the state.

The MCO will have to use its own money to pay the extra costs. But sometimes, the health care costs less than the amount of money the MCO gets. Then, the MCO gets to keep some of the extra money.

This is why some states use managed care. States like managed care because they don't have to risk losing money. MCOs like managed care because they get the chance to make money.

	Fee-for-service	Managed care
Who makes decisions about Medicaid?	Each state	Each state
Who runs the Medicaid program?	Each state	The MCO
How does the state pay for Medicaid?	The state pays every time someone gets health care.	The state pays an MCO a set amount of money. Then, the MCO pays every time someone gets health care.
What happens if health care costs more than they thought?	The state has to keep paying for health care.	The MCO has to keep paying for health care.
Who takes the risk?	The state	The MCO

Switching to Managed Care

Why are states switching to managed care?

Right now, many states use fee-for-service, but a lot of states want to switch to managed care.

Here's why:

- States pay a set amount of money to MCOs, and that costs less money than fee-for-service.
- The risk of paying for extra costs would be on MCOs, not the state.
- Some states are already using managed care, and other states want to try.

How can states switch to managed care?

States can switch their Medicaid programs from fee-for-service to managed care.

This takes a long time, and states have to follow these steps:

First, a state needs to put out a **request for proposals (RFP)**. An RFP lets insurance companies know that a state wants to switch to managed care. The insurance companies have to write a proposal, which talks about how the insurance company will run the program. They try to show the state why they are the best choice to run the program.

Then, the state chooses the insurance company (or companies) to run their managed care program. They make a deal with the insurance company, so the insurance company becomes the state's MCO.

After that, the state and the MCO make a plan to figure out the details about the managed care program. They need to figure out:

- What managed care will pay for
- How much money the state will pay the MCO
- How extra money gets spent if the MCO doesn't use it all
- How to find out if the MCO is doing a good job

What will managed care pay for?

The state and the MCO need to decide what managed care will pay for. It is too hard to switch every part of Medicaid to managed care all at once, so the switch to managed care usually happens in steps.

A managed care program might only pay for certain health care, then they add more kinds of health care as time goes on.

For example:

A managed care program may start by only paying for doctor visits.

Then, they could start paying for therapy.

A managed care program might only pay for certain groups of people, then they add more people as time goes on. This doesn't mean there are people not getting health care paid for!

The rest of the people on Medicaid still get health care paid for with fee-for-service.

Managed care usually starts with people without disabilities to give the MCO time to test out managed care. Then, managed care starts paying for people with disabilities.

People with disabilities usually need more health care, so it is good to make sure managed care works before we make the switch.

How much money will the state pay the MCO?

The state and the MCO decide how much money the state will pay the MCO. They work out how much money the MCO will get per person on Medicaid.

Managed care programs need enough money to pay for everyone.

People with disabilities usually need more health care, so our health care sometimes costs more money. Other people need less health care, so their health care costs less money.

But managed care programs get a set amount of money for each person. States and MCOs have to figure out the right amount of money for each person.

For example:

Kids usually need more health care than adults, so a state might decide to pay the MCO \$200 for every kid. But, the state will only pay the MCO \$100 for every adult.

They also decide how much money the MCO will get for each kind of health care.

For example:

A state has 200 people on Medicaid who need therapy. The state decides to give their MCO \$1,000 for each person who needs therapy, so the MCO gets \$200,000 to use for people to get therapy.

Setting the right amount of money is very important! It is bad if the state sets the amount of money too low, since MCOs won't want to run the managed care program.

There won't be enough money for health care. It is also bad if the state sets the amount of money too high, since it will cost the state too much money to keep the program going.

How will extra money get spent if the MCO doesn't use it

all?

The state decides how to use the extra money if an MCO doesn't spend it all.

States can decide to give the MCO the extra money. States can give the MCO all the extra money, or only some of the extra money. States can also decide to use the extra money to pay for other parts of Medicaid.

For example:

A state's managed care program has \$500,000 left at the end of the year.

The state decided their MCO would get half of the extra money, so their MCO gets \$250,000. The state decided the other half of the money would go to helping people get services, so the other \$250,000 goes to giving people services.

How can states know that the MCO is doing a good job?

States want to make sure people get good health care from Medicaid, and that the MCO does a good job running Medicaid.

Health care can be good, like when doctors listen to their patients. Health care can be bad, like when doctors ignore their patients. States find out whether health care is good or bad by asking questions. The state calls these questions **quality measures**.

In managed care, they get used to see if the MCO is doing a good job.

Managed care programs need to take good care of people who use Medicaid. When states make a managed care program, they make a deal with an MCO.

The state will give the MCO more money if they do a good job, and less money if they do a bad job. That makes sure MCOs can't take the state's money but not give good care. States need to know if the MCO is doing a good job or a bad job, so asking the right questions is very important.

For example:

A state starts a new managed care program, and chooses an MCO to run the program for 2 years. The MCO runs the managed care program for a year, and does a bad job running the program.

The state asks questions, and finds out the MCO did a bad job.

The state pays the MCO less money for next year. The MCO still needs to give everyone good health care, so they have to use their own money.

States plan out what questions they will ask MCOs. They need to think about different kinds of questions to ask.

For example:

- How does each person on Medicaid feel about their health care?
- How easy it is for people to get health care on Medicaid? Are certain kinds of health care harder to get than others?
- How well do different health care providers work with each other?
- How healthy is each person on Medicaid?

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, while 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, like:

- 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**, or “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, and 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, and 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, and 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.

Here is why it would be bad if MCOs only paid for LTSS in the community:

The law says that states have to pay for people to get LTSS in institutions. If MCOs don't have to pay for institutions, the state has to do it instead. MCOs might try to save money by saying lots of people who get LTSS need to be in institutions. Then, MCOs won't have to pay for those people, and more people would end up in institutions.

That would be bad, but 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, and 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, but 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, and 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, which is called **care coordination**.

Care coordination is when an MCO gets different health care providers together, and makes sure they talk to each other about one person's care.

For example:

Sydney gets LTSS in their own apartment, and they have an in-home helper.

Sydney needs to go to the doctor, so 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, and the doctor takes notes about what Sydney needs.

Later, Sydney needs to see a surgeon. Sydney's MCO works with Sydney's doctor, and makes sure Sydney's doctor shares her 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, or get LTSS in the community.

For example:

Some people on Medicaid get LTSS in institutions, but they want to get LTSS in the community instead. The MCO saves money, and uses the extra money to move people out of institutions.

Asking the right questions about LTSS can help people, too. States can ask questions to 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, and help more people move out of institutions.

The state asks questions to see if their MCO helps move people 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, and 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, so the program may not be exactly how it was before. MCOs could decide not to pay for certain kinds of health care, like getting support at night. 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, even when she is sleeping. She gets help from an in-home helper, and she has always used the same helper. Chanda's state switches to Managed LTSS. The MCO tells Chanda she can't get help at night anymore, and that 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 say in their plans that MCOs have to cover the same services the Medicaid program had before. States can make sure everyone can keep the same providers, and that MCOs 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 to 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, since paying for LTSS is different than paying for doctors.

For example:

Ned gets Medicaid, and he had a heart attack. Ned's MCO paid for his heart surgery, and to stay in the hospital. Ned's MCO only had to pay for these services once.

Ned needs LTSS after his heart attack, and he will probably need LTSS for the rest of his life. Ned's MCO pays for Ned's LTSS, and they have to keep paying for LTSS for the rest of Ned's life.

MCOs have to pay for LTSS for a long time, so 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, and 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 because 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, how long Ned stays alive after the heart attack, how much medicine Ned needs to help his heart, or 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 by talking to people with disabilities. They can ask good questions about our services, 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, so states need to make sure that MCOs want to give everyone 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, so 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, and 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, and her state has Managed LTSS. Gisele's MCO gets money to pay for Gisele to do something during the day, and they get 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 that 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, and less money for LTSS that we don't want. States can pay MCOs more money for LTSS in the community, and less money for LTSS in institutions.

Here is a good example:

Kwame gets LTSS, and 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, and less money if Kwame is separate from his community.

Kwame wants to get a job in his community. Kwame's MCO gets paid more money to help Kwame get a job, so they 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, and he 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, but 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, or 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 to 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, and they can help us get HCBS. There is usually a CIL in big cities, or sometimes there will be one CIL that helps a group of small cities.

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

P&As help people with disabilities fight for our rights, and 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, and 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. Nothing about us, without us!

- 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 so they can look at what problems come up, and figure out ways to fix the problems.
- You can be a part of a focus group or town halls in your community to 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 online surveys about Medicaid. The surveys ask how people feel about Medicaid. Then, the state looks at all the survey answers, and makes changes to Medicaid based on the answers. You can answer these surveys when your state asks about managed care. You can also tell other people to answer the survey to show your state that a lot of people care about Medicaid. You can share your ideas about making Managed LTSS work for us.

Words to Know

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, or 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.

health insurance

A way that people pay for health care. People pay a health insurance company some money every month. Then, the health insurance company pays for people to get health care.

home and community-based services (HCBS)

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 work with the state to run the state's Medicaid program.

managed long-term services and supports

When a health insurance company runs a Medicaid LTSS program. We call this "Managed LTSS" or "MLTSS" for short.

Medicaid

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

public health insurance

Health insurance run by the government.

private health insurance

Health insurance run by insurance companies.

Protection and Advocacy agencies (P&A)

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

quality measures

Questions you can ask to figure out if something is good or bad. In managed care, they are used to see if an MCO is doing a good job.

request for proposals (RFP)

When states let private insurance companies know that they want to switch to managed care.

risk

The chance that someone could lose money.