



A Self-Advocate's Guide to Medicaid

1. Medicaid Introduction and Background

What is Medicaid?

Medicaid is a health care program in the United States. Every state has its own Medicaid program. The U.S. government makes rules about Medicaid that the states have to follow.

Medicaid helps people pay for their health care. People can use Medicaid to pay for doctor's visits, medicine, disability services, and more. Right now, about 1 in every 5 people get their health care through Medicaid.

Important Phrases

There are some phrases that you will see many times in this toolkit. Here is a list of these phrases and what they mean.

Federal government: The federal government is in charge of the entire country. Sometimes we will call it "the U.S. Government."

Medicaid Coverage: Medicaid Coverage means what services Medicaid pays for. If Medicaid "covers" a service, that means that Medicaid will pay for that service.

Health insurance: Health insurance is a program that lets people pay a certain amount of money each month to an insurance company. Then, the insurance company will help them pay for health care that costs a lot of money. For example, insurance can help you pay for going to the hospital and getting medicine.

Having health insurance means you don't pay the full cost of your health care. In Medicaid, the government helps pay for health care services.

You will see other words and phrases **in bold**. If a phrase is **in bold**, you can look up what it means in the Glossary. The Glossary starts on page 27.

Who can use Medicaid?

Not everyone can get health care through Medicaid. Here are the groups of people that can use Medicaid:

- people with disabilities
- people who don't make a lot of money (in some states)
- kids
- pregnant people
- some older adults

What does Medicaid do?

Medicaid is an important part of the U.S. health system. Here are some facts about Medicaid:

- Medicaid pays for about half of the births in the U.S.
- Almost half of all kids in the U.S. get health care through Medicaid.
- Medicaid pays for more than 25% of mental health services in the U.S.
- At least 10 million kids and adults in the U.S. get Medicaid because of their disability. This includes people with:
 - physical disabilities
 - intellectual disabilities
 - developmental disabilities, including autism
 - serious mental health disabilities
 - HIV/AIDs
 - and other disabilities.

How is Medicaid Run?

Medicaid is run as a partnership between the **federal government** and state governments. The federal government is in charge of the entire country. The federal government sets some basic rules about how Medicaid should run.

Rule #1: States have to give Medicaid to certain groups of people. For example, States have to give Medicaid to kids from families without a lot of money. States also have to give Medicaid to people with disabilities who don't have a lot of money.

Rule#2: States have to use Medicaid to give people specific services. For example, Medicaid has to help pay for seeing a doctor or going to the hospital.

Rule #3: If they want, states can decide to give more services to more people.

Once states have followed the basic rules, they can make more decisions about who else gets Medicaid. States can also make more decisions about what kinds of services Medicaid covers in their state.

Each state makes different decisions about their state's Medicaid program. So, Medicaid works differently in different states.

What is Medicaid Called in My State?

Medicaid may be called something else in your state. Some states have different names for their Medicaid programs. But these programs are still Medicaid. Take a look at the list to see what Medicaid is called in your state.

Alabama - Medicaid Agency

Illinois - Medical Assistance

Arizona - AHCCCS (Arizona Health Care Cost Containment System)

Indiana - Medicaid

Arkansas - Medicaid

Iowa - Medical Assistance

California - Medi-Cal

Kansas - HealthWave

Colorado - Medicaid

Kentucky - Medicaid

Connecticut - Medicaid

Louisiana - Medicaid

Delaware - DMAP (Delaware Medical Assistance Program)

Maine - MaineCare

Florida - Florida Medicaid

Maryland - Maryland Medicaid Program

Georgia - Medical Assistance

Massachusetts - MassHealth

Hawaii - Medicaid

Michigan - Medicaid

Idaho - Idaho Medicaid Program

Minnesota - Medical Assistance

Mississippi - Medicaid

Missouri - MO HealthNet

Montana - Medicaid

Nebraska - Medicaid

Nevada - Medicaid

New Hampshire - Medicaid

New Jersey - Medicaid

New Mexico - Medicaid

New York - Medicaid

North Carolina - Medicaid

North Dakota - Medicaid

Ohio - Ohio Medicaid

Oklahoma - SoonerCare

Oregon - Oregon Health Plan

Pennsylvania - Medical Assistance

Rhode Island - Medicaid

South Carolina - Healthy Connections

South Dakota - Medicaid

Tennessee - TennCare

Texas - Medicaid

Utah - Medicaid

Vermont - Green Mountain Care

Virginia - Medical Assistance Program

Washington - Medicaid State Plan

West Virginia - Mountain Health Choices

Wisconsin - Medicaid

Wyoming - EqualityCare

Washington, D.C. - Medical Assistance Administration

What is the difference between Medicaid and Medicare?

Medicaid and **Medicare** are both programs that the government runs to help people get health care. But Medicaid and Medicare are not the same.

- The government runs Medicaid differently from Medicare.
- The government pays for Medicaid and Medicare in different ways.
- Medicaid covers different kinds of people than Medicare. Medicare is mostly for older adults (people over 65 years old). Every person who turns 65 in the U.S. can get Medicare. Some people under 65 with disabilities can also get Medicare.
- Unlike Medicaid, the amount of money you make does not affect if you get Medicare or not.

You can be on both Medicaid and Medicare. This is called being “**dual eligible**”.

2. Who Can Get Medicaid?

Who is Medicaid for?

The federal government makes rules about Medicaid. One of these rules is that states have to give Medicaid to certain groups of people. For example, states have to give Medicaid to:

- older adults
- people with disabilities who get social security payments
- kids
- pregnant people.

Even if you are in one of these groups, you can only get Medicaid if you or your family don't make a lot of money.

Examples:

- Tim has a disability and does not make a lot of money. He gets Social Security benefits that he uses to pay for food and housing. Tim can get Medicaid.
- Vera is old and she does not have very much money, so she is on Medicaid.
- Carmen has a disability. She is also a computer programmer. Carmen's job pays her \$10,000 every month. Because she makes that much money, she is not allowed to get Medicaid, even though she has a disability.

The federal government came up with a total amount of money a person or a family can earn in a year and still be able to get Medicaid. This number is called the **Federal Poverty Level**. The Federal Poverty Level is different each year. In 2017, the Federal Poverty Level is \$11,880 for one person. That is how much one person can earn in one year and still get Medicaid. The Federal Poverty Level is a little bit higher for families than for one person.

The Federal Poverty Level is not a lot of money at all. You can make more money than the Federal Poverty Level and still have trouble paying for things like food, rent, and medical care.

States have to give Medicaid to people who make less money than the Federal Poverty Level, if they are also in one of these groups:

- older adults
- people with disabilities who get social security payments
- kids
- pregnant people

The first thing states have to do is make sure that they give Medicaid to everyone who has to have it. After that, states can choose to give Medicaid to more people. States can give Medicaid to people who make more than the Federal Poverty Level if they still need help paying for health care.

Sometimes, a kid with a disability needs lots of expensive medical care, but their family makes too much to qualify for Medicaid. Even if the family has a lot of money, it might still not be enough money to pay for all the health care the kid needs. Some states have special rules for these kids. These special rules let kids with disabilities be on Medicaid even though their parents make too much money.

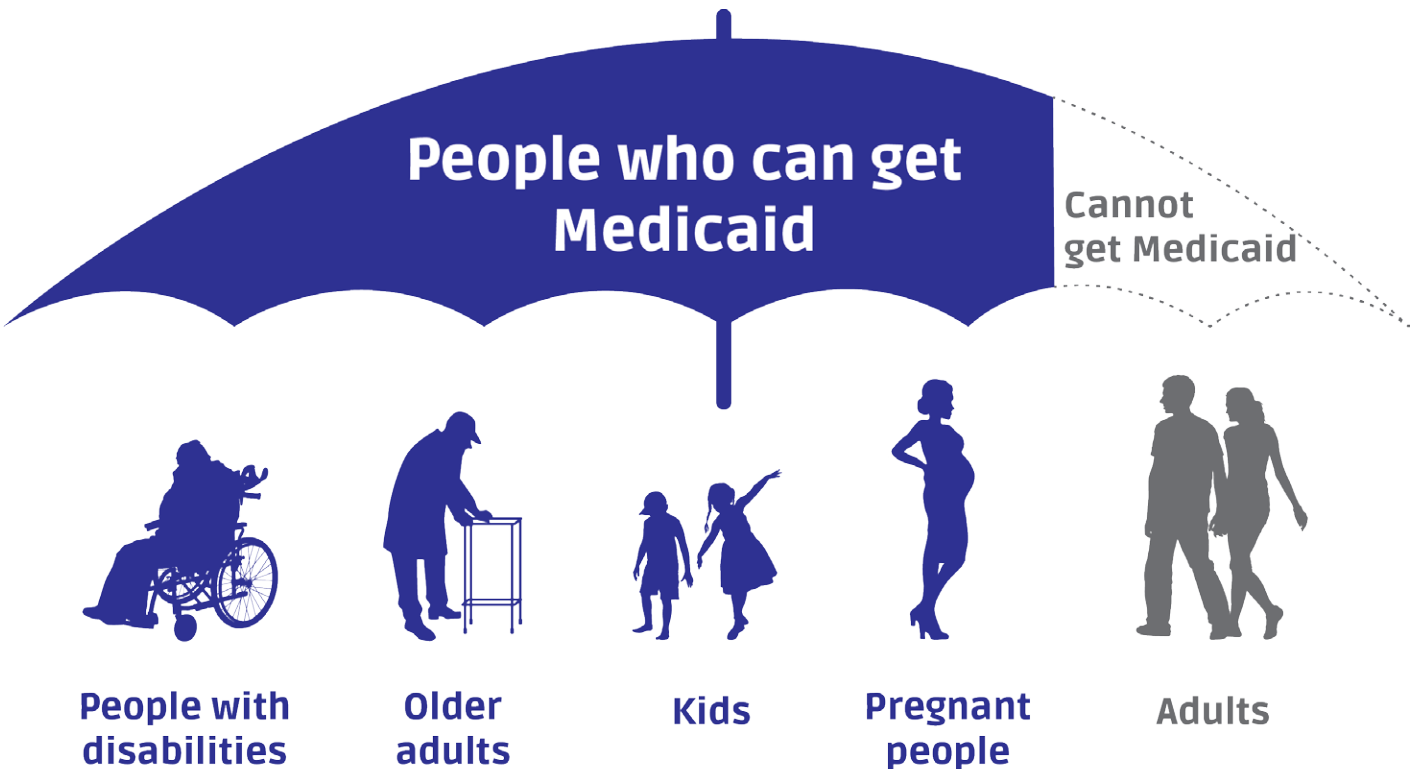
Example: George has muscular dystrophy. He needs a lot of health care and special medical equipment in order to be healthy.

George's parents are both rocket scientists. They make more money than most people. But they still cannot pay for everything George needs with their own money. The state they live in lets George get Medicaid, because Medicaid is the only way to get the kind of services George needs.

What is Medicaid Expansion?

In 2010, Congress passed a law called the **Affordable Care Act**. This law is sometimes called the ACA or “Obamacare.”

Before the Affordable Care Act

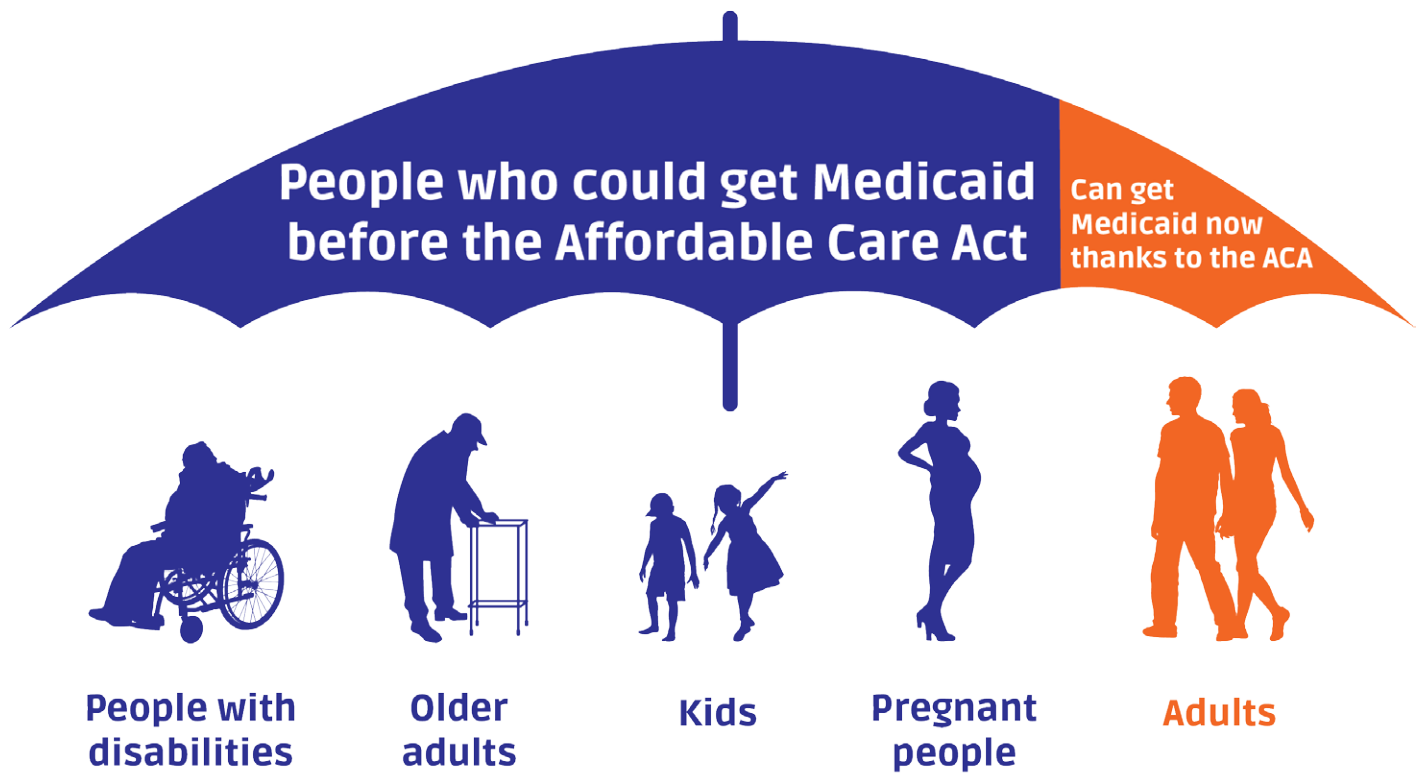


Modified from a Kaiser Family Foundation image (kff.org)

Before the Affordable Care Act, even adults who did not make a lot of money could not get Medicaid in most states. A lot of adults needed health insurance, but did not have money to buy it. Adults who could not afford health insurance could not get health care.

Adults with disabilities could get Medicaid if they did not have a lot of money. Most adults without disabilities could not get Medicaid even if they did not make a lot of money.

After the Affordable Care Act



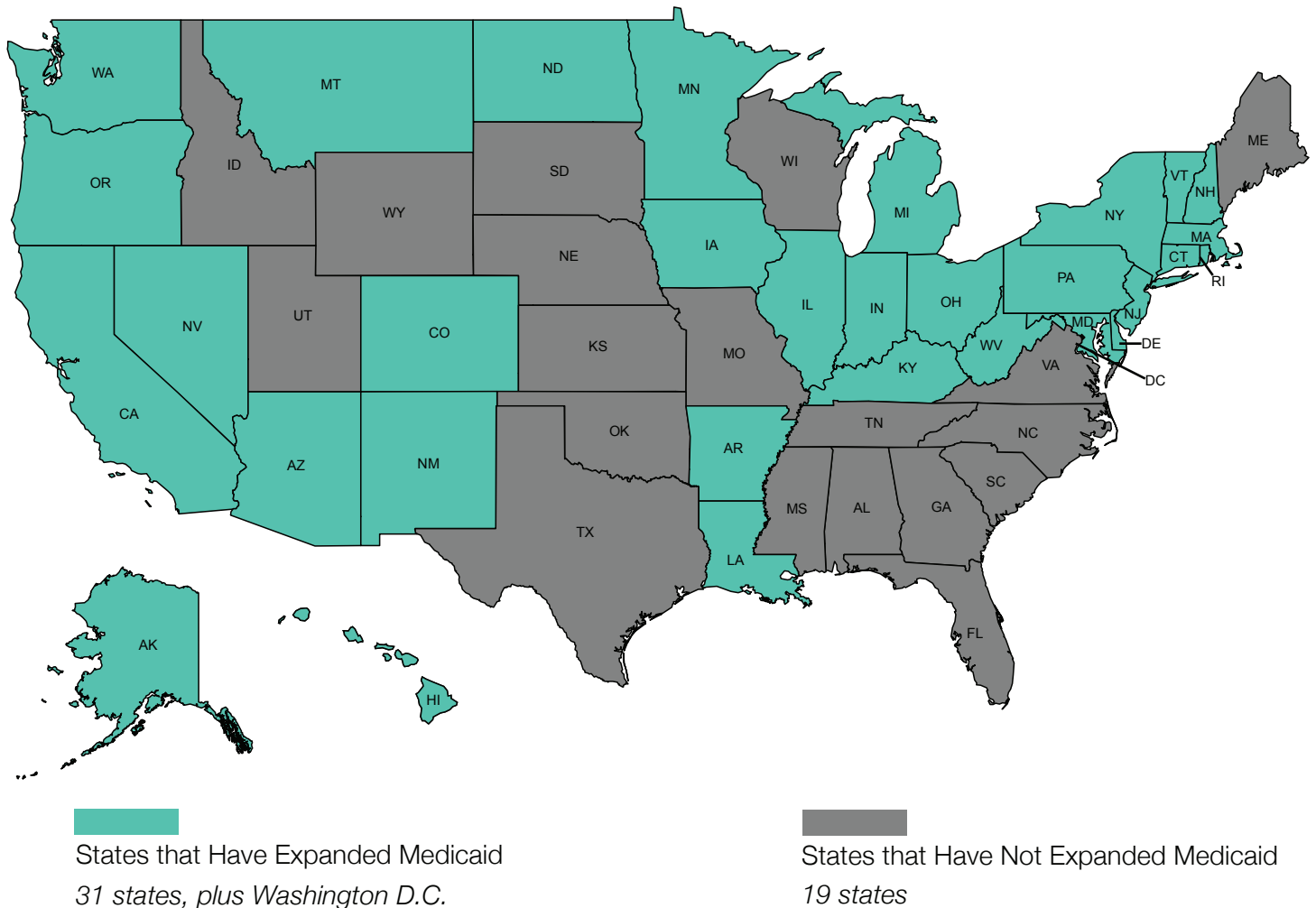
Modified from a Kaiser Family Foundation image (kff.org)

In 2014, Medicaid was **expanded** (made bigger) as part of the ACA. States got the choice to give Medicaid to all adults who do not make a lot of money. These people can get Medicaid even if they aren't in one of the groups that usually gets Medicaid.

The federal government gave extra money to states to cover this new group of people. About 17 million more people got health insurance because of the **Medicaid expansion**.

States got to choose whether to expand Medicaid or not. The map below shows which states expanded Medicaid: 19 states did not expand Medicaid and 31 states expanded Medicaid.

STATES THAT HAVE EXPANDED MEDICAID



The Medicaid expansion has helped more people with disabilities get Medicaid.

In states that expanded Medicaid, people with disabilities who do not make a lot of money can get Medicaid right away. This is important because usually people with disabilities don't get Medicaid until they are on Social Security. But, that process can take a while. With Medicaid expansion, people can start getting health care while they are applying for Social Security benefits.

3. What Does Medicaid Pay For?

What services does Medicaid cover?

Medicaid coverage refers to what services are paid for by Medicaid. If Medicaid “covers” a service, that means that Medicaid will pay for that service. Medicaid pays for lots of services that people need.

The federal government made a list of services that every state has to use Medicaid to pay for. These services are called **mandatory benefits**. These are some of the mandatory benefits that Medicaid has to pay for in every state:

- Going to the doctor
- Medical care that has to happen in a hospital, like surgery
- Staying overnight in a hospital
- Family planning services, like birth control
- Health care for pregnant people, including during birth
- Home health care (for example, if someone needs a nurse to come to their house)
- Tests to find out if kids have disabilities
- Long-term services and supports (We will talk more about what these are later)

Many states chose to include more services that Medicaid will pay for, as well as the mandatory benefits. For example, they might cover:

- Medicine
- Physical therapy
- Eyeglasses
- Going to the dentist

What are long-term services and supports?

Long-term services and supports are services that help older adults and disabled people live their daily lives. People use long-term services and supports to help with daily activities. Some examples of long-term services and supports are job coaches, transportation, nursing services, and personal care worker services. Long-term services and supports can also include things like nursing homes, group homes, and institutions.

Medicaid pays for most long-term services and supports in the U.S. Long-term services and supports can be very expensive. Private health insurance and Medicare usually do not cover them. That means that if someone needs long-term services and supports, they usually have to be on Medicaid.

Home and Community-Based Services

Home and Community-Based Services (HCBS) are Medicaid services that people get in the community. People use home and community-based services instead of going into institutions.

Some examples of home and community-based services are:

- Job coaching
- Someone to help you get dressed, take a shower, or eat
- Transportation to a job or an appointment
- Help around the house with things like cooking and cleaning
- Someone who helps you go places in your community, like the library, school, or the gym

States get to decide how they run home and community-based services in their state Medicaid programs. Home and community-based services work differently in different states. States mostly give people home and community-based services through **Medicaid Waivers**.

Medicaid Waivers

A **Medicaid Waiver** is a program that offers services to certain groups of people. Each state runs its own Medicaid Waiver programs. But, the federal government has to approve these programs. Most Medicaid Waivers are for:

- older adults
- people with certain disabilities, or
- people with illnesses that last a long time (like HIV/AIDS).

States get to decide what services people can get from their Medicaid Waivers. States also get to decide what group of people can be in a Medicaid Waiver. This means that the state can make a Medicaid Waiver for a specific group, for example:

- people with one kind of illness
- people with a specific disability
- people in a specific age group.

To get a Medicaid Waiver, people have to show that they need a lot of support in order to live in the community or get the services they need.

Medicaid Waivers are a little different from other Medicaid coverage. States can't usually have waiting lists for Medicaid coverage, but they are allowed to have waiting lists for Medicaid Waivers. That means that some people have to wait a long time before they can get the services they need.

Medicaid Waivers are very important to many people with disabilities. Many disabled people need long-term supports and services to be able to live independently in their communities. For many people, Medicaid Waivers are the only way they can pay for the long-term services and supports they need. If they can't get a Medicaid Waiver, that person might need to go into an institution instead.

4. Medicaid Funding

How is Medicaid Paid For?

Federal matching

The federal government shares the cost of Medicaid with each state. This is called **federal matching**. The federal government “matches” the money that states spend on Medicaid. In general, every time a state spends \$1 on Medicaid, the federal government gives that state another \$1 for their Medicaid program. The federal match can be different depending on the state or the Medicaid program. The federal government also gives more money to states where more people need help.

As long as states follow federal rules, the federal government will match what states pay. If a state pays more for Medicaid, the federal government pays more for Medicaid. If a state pays less, the federal government pays less.

States need federal matching for Medicaid. Without federal matching, states would not have enough money for their Medicaid programs. If they didn't have federal matching, the states wouldn't have enough money to give services to everyone who gets services now. They would have to get rid of some services that Medicaid covers, or cover fewer people

Why is Federal Matching Important?

One important thing about Medicaid is that Medicaid can get bigger or smaller depending on how many people need it. Medicaid can do this because of federal matching.

The economy affects Medicaid

If the economy is bad, fewer people have jobs and more people may need Medicaid. When the economy is bad, not as many people can afford to buy health insurance. They need Medicaid. So when the economy is bad, Medicaid gets bigger. Medicaid gets bigger because more people need it. The state can afford to make Medicaid bigger because the federal government is helping them pay for it.

If the economy gets better, some people will start making more money again. They can get health insurance on their own. They won't need Medicaid anymore. So when less people need Medicaid, Medicaid gets smaller again.

Medicaid can grow based on each state's needs

Medicaid can grow based on needs in each state. This helps states to deal with health problems that they may not have expected.

Example #1: There could be an unexpected disease that makes many people in a state sick. Medicaid would pay more money to cover the services that people need to get better.

Example #2: A new medicine is created. The medicine costs more money. Medicaid can spend more money to pay for the new medicine.

Medicaid is able to grow in these ways because of federal matching. Federal matching is important because Medicaid is a partnership. When one partner pays less, the other partner has to pay more.

The federal government has more money than states do. The federal government has extra money to spend on surprise costs. States do not have extra money to spend on surprise costs. Without federal matching, states could not spend more money on Medicaid when they need to, like when there are unexpected health problems.

5. What Could Happen to Medicaid?

What Could Happen to Medicaid if the Funding Changes?

There are some people in the government who want to change how the government pays for Medicaid. These people want the federal government to pay less for Medicaid. There are two different ideas that people are talking about:

Idea #1: Changing Medicaid funding to a **block grant**.

Idea #2: Changing Medicaid funding to a **per capita cap**.

Either one of these ideas would be a huge change to Medicaid. States would get less money from the U.S. government. To make up for getting less money, states would need to either raise more money for Medicaid, or make Medicaid cost less.

If states wanted to raise more money for Medicaid, they would need to raise taxes. Many people don't like when states raise taxes. So states would probably find ways to make Medicaid cost less. One way states could make Medicaid cost less is by taking Medicaid away from some people. Another way could save money is by not paying for as many Medicaid services.

What is a Block Grant?

A **block grant** is a set amount of money that the federal government decides in advance to give each state. The way that the federal government helps states pay for Medicaid would look very different if Medicaid were funded by block grants.

First, the federal government would decide how much money to give each state in a block grant. Different states would get different amounts of money. Next, the federal government would pay that money to the state once a year. Then, the states can put that money towards running Medicaid in their state.

How Would a Block Grant Work?

No federal matching

If Medicaid funding becomes a block grant, there would be no federal matching anymore. States would get a set amount of money from the federal government once a year. After the block grant money is used up, states would pay for the rest of the costs out of their own money. Even if more people need Medicaid or if people need more services, the federal government wouldn't give states any more money for Medicaid.

States would get less money

Block grants would also change the *amount* of money that the government gives states. If Medicaid changed to block grants, the government would give states a lot less money than it gives them now.

For example, let's talk about the plan that Congress is thinking about now. In this plan, the Federal government would spend \$880 billion less on Medicaid over the next 10 years. The plan is for the amount of money in the block grants to stay smaller than health care costs.

Every year, health care costs grow. But the plan says that even when health costs grow, states would not get more money to pay for these costs. This means that over time, states would pay more and more money for Medicaid, and the federal government would pay less money. This would change how states are able to run Medicaid.

If states wanted to keep the same amount of Medicaid, but the federal government paid less, the states would have to pay more. States can't spend extra money as easily as the federal government can. Most of the money states have is for things besides Medicaid. States use money for things like fixing roads, having police officers, and running schools.

Since states want to keep their roads, schools, and police officers, *and* they may not be able to raise taxes, they will probably decide to spend less money on Medicaid. Here are some things states might do to spend less on Medicaid:

- States could make it harder for people to get Medicaid
- States could limit the number of people who can get Medicaid
- States could have waiting lists for people who need Medicaid
- States could limit how many Medicaid services people can get
- States could stop paying for certain Medicaid services, like home and community based services
- States could pay doctors and health care providers less money for Medicaid services

This would be a big change from how Medicaid works now.

What is a Per Capita Cap?

What does “per capita cap” mean?

A per capita cap is a kind of block grant. A “cap” is a limit. “Per capita” means “for each person.” A “per capita cap” is a limit for each person.

What does a per capita cap do?

With a per capita cap, the federal government decides how much money a state gets for each person on Medicaid. The federal government would pay a state more or less money based on how many people are in that state’s Medicaid program. Just like block grants, per capita caps on Medicaid limit how much money the federal government gives states.

Each person who signs up for Medicaid would have a limit on how much their services can cost. If someone needs more Medicaid services, states would have to pay for any costs above the limit. States would have to pay these costs without any help from the federal government.

How Would the Per Capita Cap Work?

States would get less money

Right now, if more people in the state need Medicaid, the federal government will pay the state more since they match costs. States can depend on this matching when they think about costs. Also, if the people who are already using Medicaid get sicker and need more health care, the federal government will pay the state more. A per capita cap would change that.

With a per capita cap, the federal government would still give states more money when more people need Medicaid. But the federal government would *not* give states more money if the people who are using Medicaid need more health care, or if health care gets more expensive.

Example #1: A state might have an unexpected health situation. It could be a disease that makes a lot of people in the state sick. States would not get any extra help from the federal government to fight the disease.

Example #2: A new medicine could be created that costs more money. States could not ask for more funding from the federal government to pay for that medicine.

Effects on people with disabilities

People with disabilities often need more Medicaid services than people without disabilities. This means that it can cost more money for Medicaid to cover a person with a disability. Almost half of all Medicaid spending is for services for people with disabilities. Without federal matching, states will have a hard time giving people with disabilities the Medicaid services they need.

Just like a block grant

Like with block grants, per capita caps would get rid of federal matching as it is today. Like with block grants, per capita caps would mean the federal government gives states less money. Like with block grants, states might end up taking Medicaid away from people, or cutting services like home and community based services.

Other Changes That Could Happen

Making people on Medicaid pay more money

Medicaid is supposed to give health care to people who need help paying for it. Because of this, Medicaid has rules that limit how much money the people in the program have to pay. Some people in government want to get rid of these rules.

Without these rules, people using Medicaid would have to spend more of their own money, even if they don't have a lot. This means people wouldn't be able to afford the health care they need, even with Medicaid. And if they can't pay, they might get kicked off Medicaid. Then they would have no health care at all.

Work requirements

Some people want to make a new rule. The new rule would say that if an adult gets Medicaid, they need to have a job. This is a problem because some people on Medicaid can't work. People who can't work still need health care.

Examples:

- Kimi is being treated for cancer. She is too sick to work right now. She might be sick for a long time.
- Ravi takes care of his mom. Ravi's mom has Alzheimer's and needs a lot of help. Ravi had to stop working so he could take care of his mom.
- Monica is going to college. She needs Medicaid to pay for her wheelchair. If she had to work, she couldn't finish college.
- Ezra has a mental health disability that makes it hard for him to work full-time right now. Medicaid helps Ezra pay for his medications and therapist. If Ezra lost his Medicaid because he did not have a job, he might not be able to pay for his medications anymore.

- Shiro is autistic. Medicaid pays for Shiro to get a job coach to help him find a job. If Shiro did not have Medicaid because he did not have a job, he might not get the help he needs.

Even if someone can't work, they still need health care. That's why it is so important that even if someone can't work, they can still get Medicaid.

6. Summary & Glossary

Medicaid is an important part of the U.S. health care system. Medicaid is the biggest health care program in the country.

Medicaid pays for services that other types of health insurance don't cover. For example, Medicaid pays for most of the services that help people with disabilities live in the community.

Medicaid covers many people who would not have access to health care without it. This includes children, older adults, and people with disabilities.

Medicaid is a partnership between the U.S. government and state governments. This partnership is how Medicaid is able to serve so many people. The federal government and states share the cost of providing Medicaid. This is an important part of the partnership.

States do not have extra money to spend on surprise costs. The federal government can spend extra money more easily than states can. So the federal government "matches" the money that states spend on Medicaid. In general, every time a state spends \$1 on Medicaid, the federal government gives that state another \$1 for their Medicaid program. That way, states can be sure they are able to cover people who need Medicaid in their state.

Glossary

Affordable Care Act (ACA)

The Patient Protections and Affordable Care Act is a law that was passed in 2010. People call it the Affordable Care Act or the ACA for short. Some people also call it Obamacare, because Barack Obama was the President who helped make the law. The ACA made it easier and fairer for people to get health insurance.

block grant

A set amount of money that the federal government gives to each state to run Medicaid. Block grants are one idea about how to change how Medicaid is paid for.

dual eligible

A person who qualifies for both Medicare and Medicaid.

eligible

Meeting the requirements to get Medicaid.

federal government

The government that is charge of the entire country and is based in Washington. D.C.

federal matching

The federal government “matches” the money that states spend on Medicaid. In general: Every time a state spends \$1 on Medicaid, the federal government gives that state another \$1 for their Medicaid program.

federal poverty level (FPL)

How much money a person can make to be eligible for Medicaid or other government programs.

health insurance

A program that lets you pay a certain amount of money each month to an insurance company. Then, the insurance company will pay for part of your medical costs.

home-and community-based services (HCBS)

A type of service, paid for by Medicaid, that are offered in home and community settings instead of in an institution.

long-term services and supports (LTSS)

Services that help older adults and people with disabilities with day-to-day activities that help them live independently.

mandatory benefit

Services that have to be covered by Medicaid.

Medicaid

A health care program in the United States.

Medicaid coverage

The services that are included in the Medicaid plan or in other words how much is an individual “covered” by the Medicaid plan.

Medicaid eligibility

Describes whether someone can have Medicaid or not. If a person is eligible, it means they meet the requirements to have Medicaid.

Medicaid expansion

A new part of the Affordable Care Act that allows adults with a low income, whose income is below 138% Federal Poverty Level (FPL).

Medicaid Waiver

A state-run Medicaid program that gives HCBS services to certain groups of people.

Medicare

A government run health insurance program in the U.S. Medicare is mostly for older adults (people over 65 years old) and some people under 65 with disabilities.

per capita cap

A “cap” or limit on the amount of money that the federal government pays states for each person who signs up for Medicaid. A per capita cap is one plan to change how Medicaid is paid for.