

A Self-Advocate's Guide to the Affordable Care Act



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Using the Affordable Care Act Toolkit

What is this?

This toolkit is about the Affordable Care Act, also known as the ACA or “Obamacare.” This resource will explain:

- What the ACA is
- How different parts of the ACA improved health care in America
- How the ACA could be repealed
- What would happen if the ACA is repealed

How can I use this?

You can read this toolkit from beginning to end, or go straight to the parts that you want to know more about. The first section, “Introduction,” defines what the ACA and health insurance are. “What are the main parts of the ACA?” explains more about the important parts of the law. There are a lot of these, but they include:

- Medicaid expansion
- the Individual Mandate, and
- covering pre-existing conditions.

“How does the ACA affect me?” shows the different ways that the ACA has changed health care for different groups of people. “What could happen to the ACA?” talks about what would change if Congress gets rid of specific parts of the ACA. “What happens if the whole ACA is repealed?” explains what would happen if Congress chose to get rid of the entire ACA at once, instead of just changing specific parts.

Glossary

Throughout this toolkit, you will see words and phrases in **bold**. These important phrases are included in the Glossary starting on page 13.

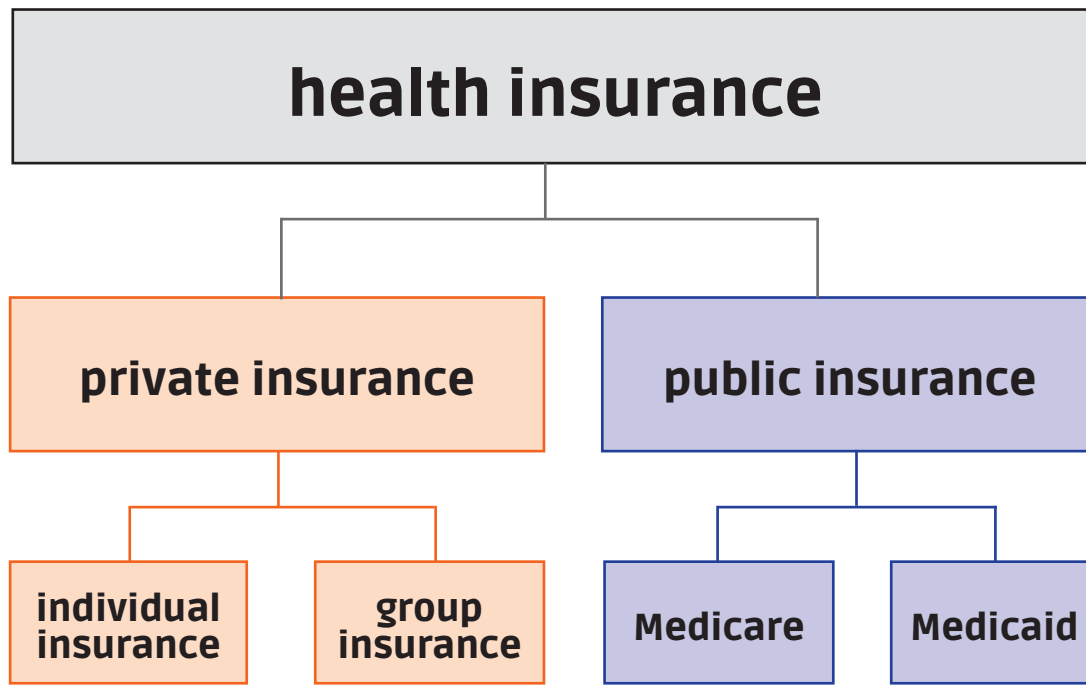
Introduction

What is the Affordable Care Act?

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. “Obamacare” and the Affordable Care Act (ACA) are the same thing. The ACA made it easier and fairer for people to get **health insurance**.

What is health insurance? Why does it matter?

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, going to the hospital or getting medicine. There are a few different places and ways that people can get health insurance.



Most health insurance in the United States is **private**. This means that the health insurance program is run by a company, and not the U.S. government. People can get health insurance as an individual or in a group.

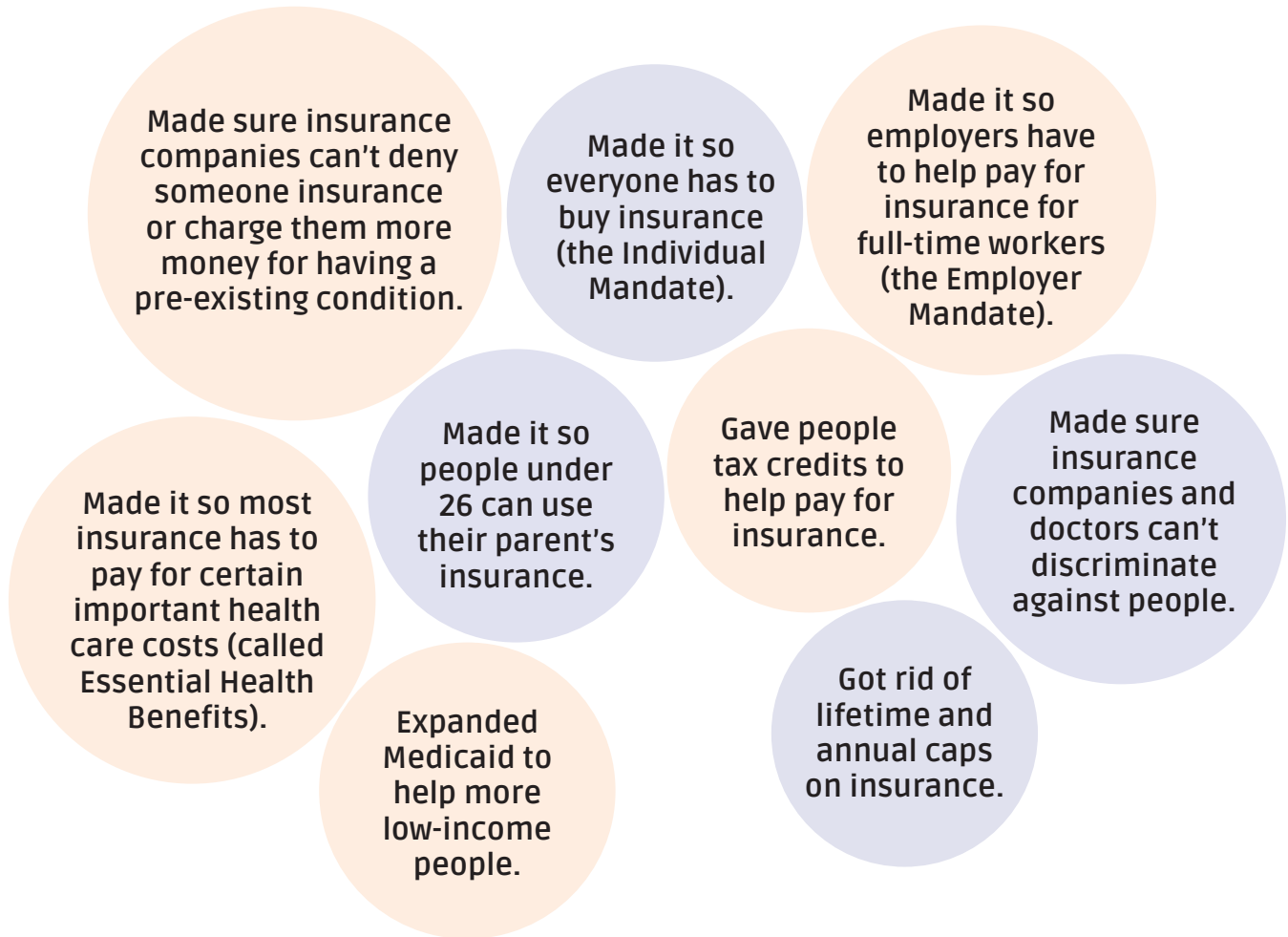
Group insurance is when a group buys insurance to cover a lot of people at the same time. This is usually done by companies to pay for insurance for their workers. Employers will decide what kinds of insurance plans to offer their employees. The employers will pay for some or all the cost.

Individual insurance is when one person, a family, or a small business buys insurance by themselves. Before the ACA was passed, individual insurance was very expensive. Many people could not afford individual insurance. Also, individual insurance companies turned away everyone with certain disabilities or health conditions. We will talk later about how the ACA changed this.

There are a couple of ways to get insurance that are public. **Public health insurance** is run by the U.S. government and paid for by taxes. **Medicaid** helps low-income people and people with disabilities by giving them health insurance. **Medicare** is health insurance given to anyone over the age of 65. Some people under age 65 with disabilities can also get Medicare.

What are the main parts of the ACA?

The ACA made many rules that protected the rights of people to get health insurance. It also made it easier for people to afford health insurance. The ACA made rules that most private companies have to follow when giving people health insurance. It also made rules that individuals, employers, and hospitals have to follow. All of these rules made it so that more people can get cheaper health insurance that will pay for the health care they need. Here is a quick summary of the most important things the ACA did:



Pre-existing Conditions

Before the ACA was passed, it was harder for people with **pre-existing conditions** to get health insurance. People with “pre-existing conditions” are people who were sick or disabled before they tried to buy insurance. Some examples of pre-existing conditions are:

- Chronic ear infections
- Autism
- Cancer (even if you don't have it anymore)
- High blood pressure
- Allergies

There are many diseases, disabilities, and other health problems that are considered pre-existing conditions. Some people think that up to half of Americans have a pre-existing condition.

Insurance companies could refuse to give individual insurance to people with pre-existing conditions. Insurance companies could also do something called “**medical underwriting**.” This means companies would first look at someone’s medical history. Then, they would decide what price they were going to charge that person for insurance. If an insurance company thought that someone might need to see a doctor often, they could charge that person more money. They could make the price of insurance so high that the person wouldn’t be able to pay for it. This is called being “priced out” of insurance.

If someone got sick or became disabled after they got insurance, insurance companies were allowed to stop giving that person insurance. They could also raise the price of that person’s insurance until the person couldn’t pay for their insurance anymore.

The ACA made all of this illegal for insurance companies to do. Insurance companies now have to charge everyone the same amount for the same kind of health insurance, no matter how sick or healthy the person is. This helps a lot of sick and disabled people get and keep insurance that they can afford.

Annual and Lifetime Caps

Before the ACA was passed, insurance companies could stop paying for a person’s insurance if that person hit a “cap” on their insurance. The cap is a certain amount of money a person can use for health care. **Annual caps** are how much money a person can use over a year. **Lifetime caps** are how much money can be used over their whole life. Once a person hit this “cap” on their insurance, they would have to pay for all the rest of their health care by themselves. This hurt a lot of sick and disabled people who needed a lot of health care and couldn’t afford it by themselves. The ACA made these caps against the law. Now, there is never a limit on how much health care an insurance company will pay for per person.

Essential Health Benefits

Before the ACA was passed, every health insurance company had different rules about what health care they would pay for. Insurance companies could try to save money by refusing to pay for certain kinds of health care that people needed. The ACA changed this. The ACA made a rule that most health insurance has to help pay for 10 types of health care. These types of health care are called “**Essential Health Benefits**”. These essential health benefits include:

1. Outpatient services (like going to a doctor’s appointment)
2. Emergency services
3. Hospitalization (like surgery and staying at the hospital overnight)
4. Care during pregnancy and for newborn babies
5. Treatment for mental health disabilities
6. Prescription drugs
7. Rehabilitative and habilitative services and devices (like physical therapy, occupational therapy, or speech therapy)
8. Laboratory services (like blood tests)
9. Preventive care services (like getting vaccines and regular check-ups)
10. Health care for children

Having all of these important health care areas paid for by insurance helps people be able to get the care they need no matter what insurance they have.

Tax Credits

Before the ACA was passed, a lot of people could not afford to get any health insurance at all. This is because getting individual insurance was so expensive. The ACA made it so that when someone who makes less than \$47,000 per year buys individual insurance, the government will pay part of the cost. Parents and married couples can make more than that and still get help paying for insurance. This made it easier for people to get insurance who could not pay for it before.

Employer Mandate

Before the ACA, employers didn't have to help their employees pay for health insurance. The ACA made it so that most companies have to pay for health insurance for full-time employees. This helped a lot of people who weren't getting health insurance through their job before. The ACA also gave small businesses tax credits to help their employees get insurance.

Individual Mandate

Before the ACA, there was no rule saying that everyone had to buy health insurance. This meant that a lot of people wouldn't buy health insurance because they didn't think they needed it. This made health insurance more expensive for the people that did need it. The ACA made it so that by law, everyone has to have health insurance, or else they will pay a fine.

This rule is important for two reasons. First, you never know when you will need health insurance. If someone who didn't think they needed health insurance suddenly got into an accident or got a disease, they will now have insurance to pay for it instead of having to pay for it all by themselves. Second, when everyone is paying for health insurance, it means that insurance companies can charge each person less for health insurance.

To make it easier for individuals to get health insurance, the ACA made insurance "marketplaces" where people could go online and compare prices for health insurance. This makes it easier for people to find an insurance option that works for them.

Extending Parent's Health Insurance to Age 26

Before the ACA was passed, children could be kicked off of their parent's health insurance plans as soon as they turned 18. This could be a big problem for people who just turned 18 and became adults, who may not have a job yet. The ACA made it so that children could use their parent's health insurance until they turn 26. That way, they don't have to worry about getting their own health insurance right away.

Medicaid Expansion

Before the ACA was passed, it was a lot harder for people to get Medicaid. The ACA made it so that more people could get Medicaid. This is called the **Medicaid Expansion**. Medicaid helps low-income people and people with disabilities by giving them health insurance. Because of the Medicaid Expansion, 11 million new people were able to get Medicaid.

Anti-Discrimination Rule

Before the ACA, insurance companies could choose not to pay for certain health care services for a person based on who they were. For example, they could choose not to pay for cancer treatments for someone with a history of cancer. This is because they thought it would get too expensive. Or they could choose not to pay for things like birth control or HIV screenings for someone who is transgender. Both of these examples are discrimination. Discrimination made it harder for people to access the health care they needed.

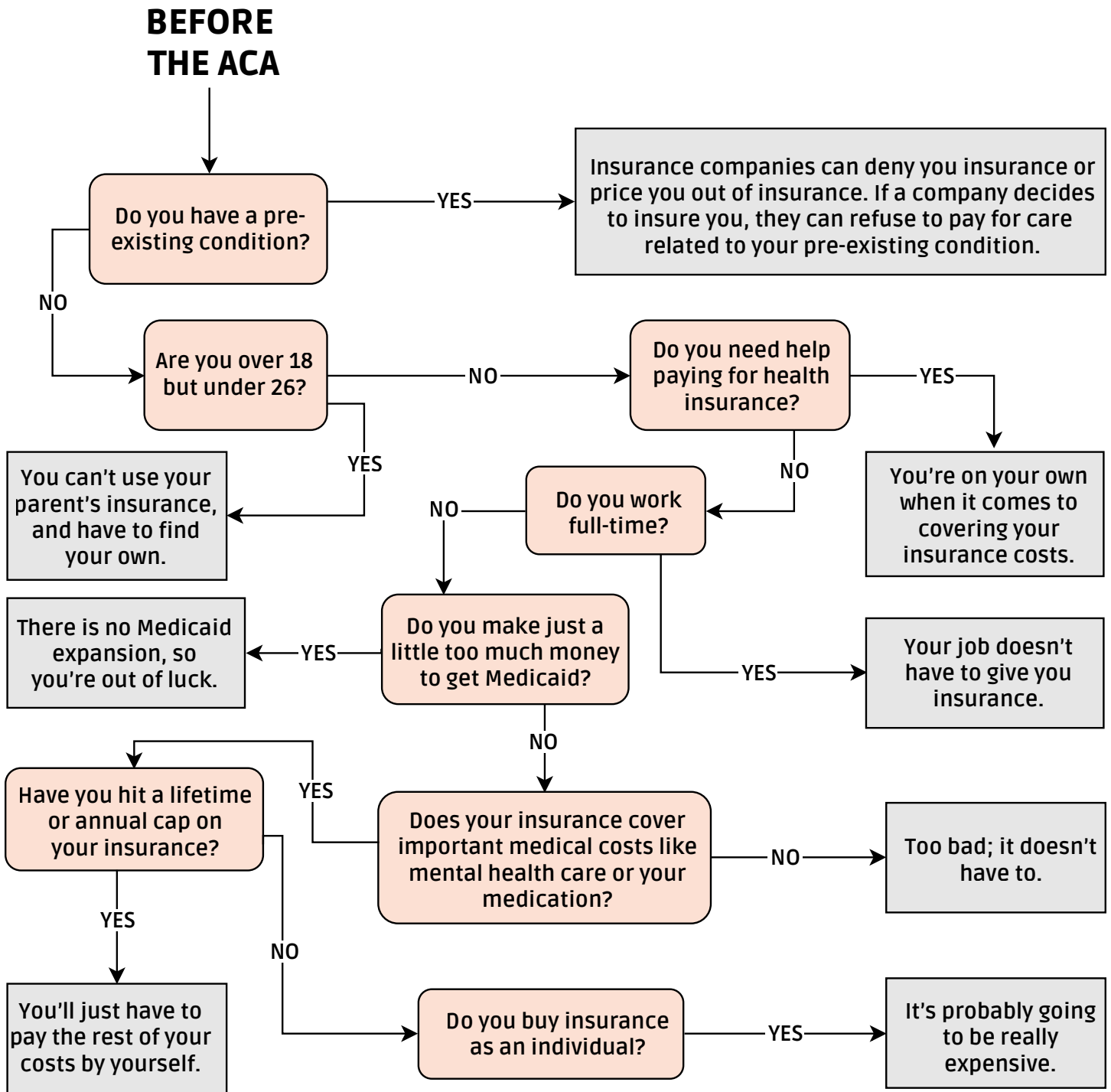
The ACA made it so that insurance companies have to pay for the same services for people using the same insurance plan. They can't choose to not pay for someone because of things like their:

- gender
- race
- sexual orientation, or
- disability status.

This rule also applies to people that give health care, like doctors. Health care providers can't choose not to give someone medical care because of who they are. This helps people get the care they need and feel better about going to the doctor.

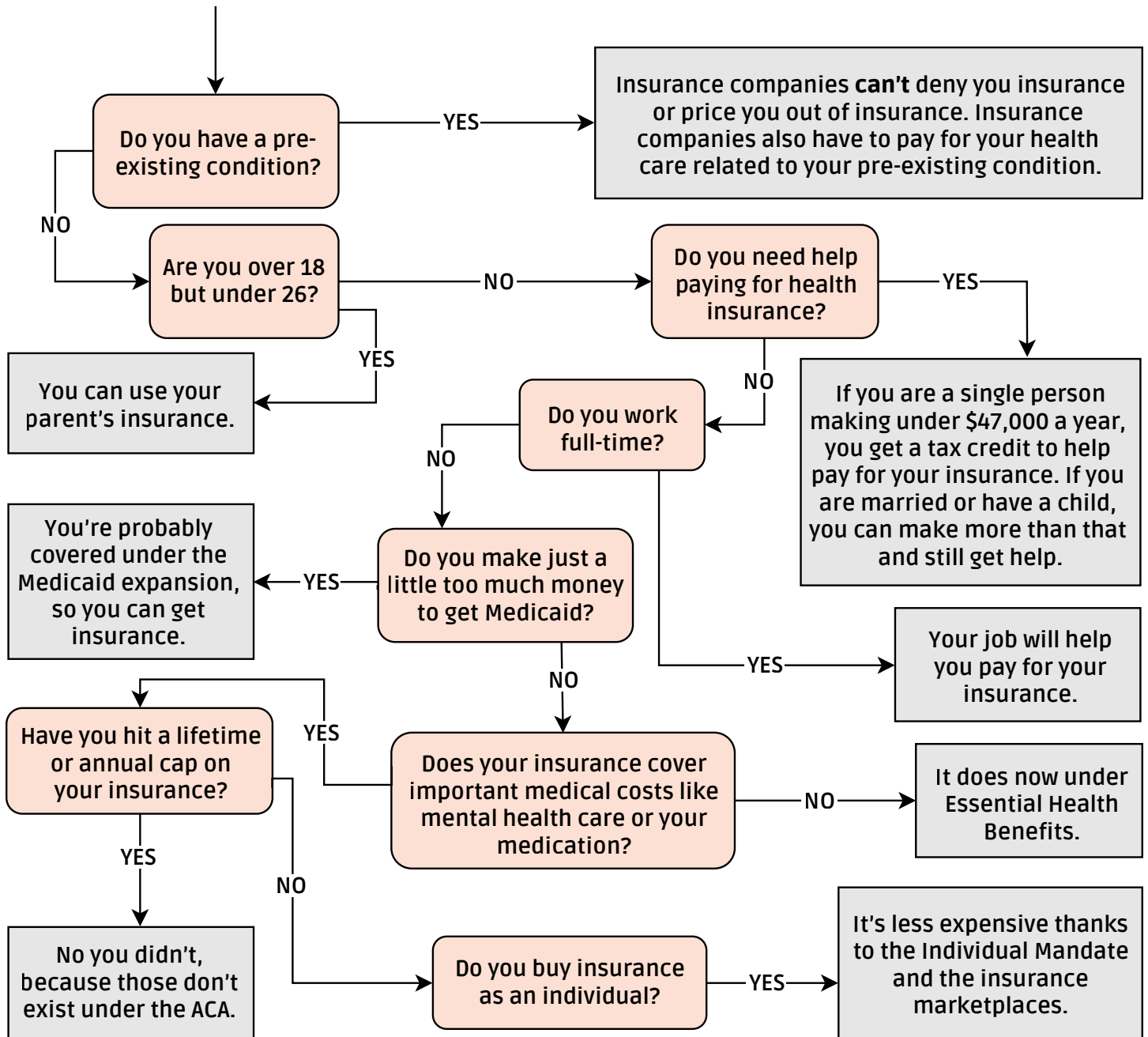
How does the ACA affect me?

Before the ACA



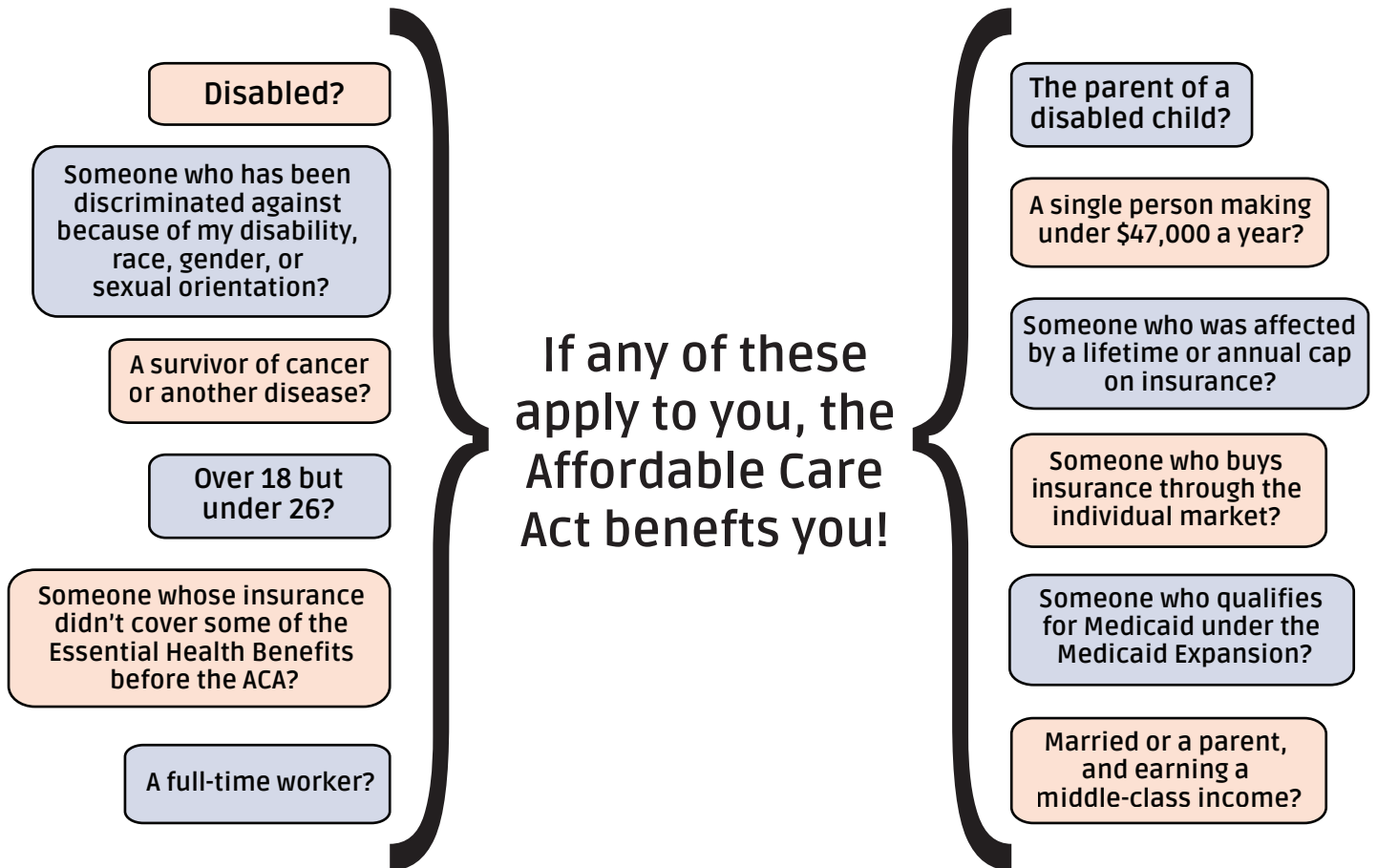
After the ACA

AFTER THE ACA



Does the ACA benefit me?

Ask yourself: Am I...

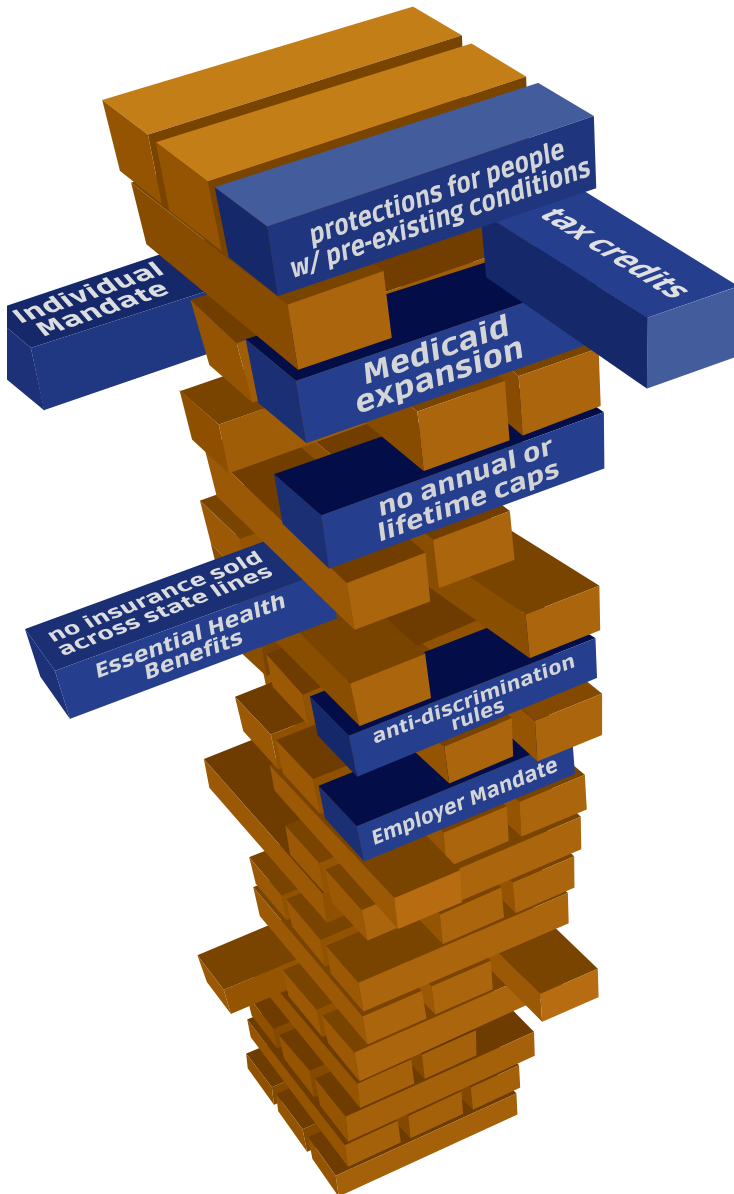


What could happen to the ACA?

There are some people in the government that want to repeal, or get rid of, the ACA. Doing this could mean that health insurance and insurance companies would go back to the way they were before the ACA was passed. A lot of people could lose their health insurance, and may not be able to get it back. That means that if they got sick or injured, they may not be able to pay to get help.

The government could choose to get rid of only certain parts of the ACA, or they could choose to get rid of all of it. But every part of the ACA is important. Let's talk about why:

What parts of the ACA could change?



Get rid of the Individual Mandate

The government could decide to take out the part of the law that says that everyone has to buy health insurance. This is the Individual Mandate. This would be a problem because some people would choose not to buy insurance until after they started needing a lot of health care. This would make insurance more expensive for everyone. A good law should make sure that everyone has insurance.

Get rid of the Employer Mandate

The government could decide to take out the part of the law that makes employers pay for health insurance for their employees. This is the Employer Mandate. This would be a problem because a lot of workers would lose their health insurance, and may not be able to afford it on their own. A good law should make sure that employers help cover the health insurance for their workers.

Get rid of Essential Health Benefits

The government could decide to take out the part of the law that makes sure that health insurance covers Essential Health Benefits. This would be a problem because health insurance companies could choose to not cover certain important health care needs in their insurance plans. Then, people with health insurance might not be able to use their insurance to pay for the care they need. A good law should make sure that important health care costs like the Essential Health Benefits are always covered in every insurance plan.

Allow insurance to be sold across state lines

The government could decide to let insurance companies sell their insurance across state lines. If the government did this, and got rid of Essential Health Benefits, some states could decide to have no rules at all about what insurers need to cover. Then all insurance companies could decide to sell their insurance from that state. They could sell insurance for cheap because they don't have to cover anything. People might buy the insurance and not realize until it is too late that it won't cover what they need. A good law should make sure that insurance companies sell insurance that people are able to use to get what they need.

Get rid of protections for people with pre-existing conditions

The government could decide to get rid of the rules about pre-existing conditions. This is a problem because insurance companies could deny someone insurance because of a disease or disability. Or, they could use medical underwriting to charge them more money because of a disease or disability. A good law should make sure that people with pre-existing conditions can get the same insurance coverage at the same price as people without pre-existing conditions.

The government could decide to replace the rules about pre-existing conditions with something called “**high-risk pools**”. High-risk pools are when a state gives money to an insurance company. This money is put aside only for people with pre-existing conditions to use for insurance. High-risk pools were around since before the ACA. But even with this money set aside, people with pre-existing conditions still couldn’t afford insurance. On top of this, high-risk pools still have annual and lifetime caps. A good law should make sure that people with pre-existing conditions can get the same insurance coverage at the same price as people without pre-existing conditions.

Bring back lifetime and annual insurance caps

The government could decide to get rid of the rule about annual and lifetime caps on insurance costs. This is a problem because people who hit these caps can’t afford to pay for their health care without the help of insurance. A good law should make sure that annual and lifetime caps don’t come back.

Get rid of the Medicaid expansion

The government could decide to get rid of the Medicaid expansion. This is a problem because 11 million people get their health insurance through the Medicaid expansion. Getting rid of it means that a lot of people would lose their insurance right away. These people don’t make enough money to afford their own insurance. A good law should make sure these people on Medicaid don’t lose their insurance.

Get rid of tax credits

The government could decide to get rid of tax credits for insurance. This is a problem because a lot of people can only afford health insurance now because of these tax credits. A good law should make sure that people using these credits can continue to afford insurance.

Get rid of the anti-discrimination rule

The government could decide to get rid of the anti-discrimination rules. This is a problem because insurance companies and medical providers could choose to deny someone the health care they need because of things they can’t control, like their:

- gender
- race
- disability, or
- sexual orientation.

A good law should make sure that any person can get the health care they need without being discriminated against.

Every part works together

Each part of the ACA is equally important, and would hurt a lot of people if it were reversed. A lot of the parts of the ACA also work together. For example:

- giving people tax credits to buy insurance helps people not break the Individual Mandate rule, and
- making sure that everyone buys insurance makes it easier for insurance companies to afford to cover people with pre-existing conditions at a fair price.

Each part of the ACA should stay the way it is for the law to work the best.

What happens if the whole ACA is repealed?

The government could choose to just get rid of the whole ACA instead of keeping certain parts. People who want to get rid of the ACA say that they will come up with a replacement for it. They call their plan “repeal and replace.” This is because they want to come up with a better version of the ACA after they get rid of it.

Some of the people in government who want to repeal the ACA say they want to give people “**universal access**” to insurance. That means that everyone should be able to get insurance. While this sounds like a great idea, this isn’t the same thing as “**universal coverage**.” Universal coverage is when everyone can get insurance that will actually pay for the health care they need, like Essential Health Benefits. The Affordable Care Act focuses on universal coverage. This is because it has rules to make sure that everyone can pay the same amounts for the same plans. People in the government who support universal access may do things to make insurance cheaper. But, they wouldn’t keep the rules the ACA has about coverage. So even if someone could get health insurance through an ACA replacement law, it may not cover the health care they need to survive.

Right now, there haven’t been any ideas from the government about a replacement that would make sure everyone who gets insurance through the ACA can keep their insurance. This is a problem because the ACA may be repealed very soon. What might happen instead is that the ACA will get repealed without any replacement. The government will instead put off coming up with a replacement for as long as they can. During this time, certain parts of the ACA may be kept. But, the money that funds the Medicaid expansion and tax credits would be taken away. This would make it harder for the government to make sure the rest of the ACA’s rules are being followed. Some people call this plan “**repeal and delay**.”

To repeal the ACA and delay coming up with a replacement would hurt millions of Americans. People would lose their insurance and not have any other options to get it back. This especially hurts people with pre-existing conditions and low-income people. Without the ACA, these people could be denied or priced-out of insurance again.

Summary: Why would it hurt people to get rid of the Affordable Care Act?

There are 20 million people who have insurance now who didn’t before, thanks to the ACA.

- There are young adults who can now use their parent’s insurance until they turn 26.
- There are people who couldn’t afford insurance before who can get it now because the government helps them pay for it.
- There are people who couldn’t get Medicaid before who can get it now.
- There are people who couldn’t get insurance because of their illness or disability who can get it now.
- There are workers who now can get insurance through their employers.

The ACA also helped millions of people who already had insurance.

- There are people that didn’t have some of their health care needs paid for by insurance before, who can now get this help thanks to the Essential Health Benefits rule.
- There are people who were in danger of getting kicked off or priced out of their insurance before because of their illness or disability, who will be able to keep their insurance now.
- There are people who were in danger of reaching their insurance “cap” and having to pay for all their health care, who don’t have to worry about that anymore.
- There are people who were discriminated against when trying to get certain health care needs covered by insurance, who have those needs covered now.

Getting rid of the Affordable Care Act hurts a lot of people, but it will hurt disabled people in particular. Disabled people usually have to get more healthcare than non-disabled people. So, a disabled person may not be able to live without health insurance helping them pay for their care. The ACA made a lot of rules to help protect disabled people from ways that insurance companies could unfairly control their health insurance because of their disability. If the ACA was gone, disabled people would not have that protection anymore. A lot of disabled people would stop getting the insurance that they were finally able to get thanks to the ACA.

Glossary of Terms

Affordable Care Act (ACA)

See Patient Protections and Affordable Care Act (PPACA).

annual cap

Before the ACA was passed, insurance companies could stop paying for a person's insurance if that person used too much money, or hit their "cap", for health care over a year.

employer mandate

This refers to the Affordable Care Act provision that made it so that most companies have to pay for health insurance for full-time employees.

Essential Health Benefits

Essential Health Benefits are 10 types of health care that most health insurance has to help pay for under the Affordable Care Act, including emergency services, preventive care services, and treatment for mental health disabilities.

group insurance

Group insurance is when a group buys insurance to cover a lot of people at the same time.

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, like going to the hospital or getting medicine.

high-risk pools

High-risk pools are when an insurance company is given money by a state to be put aside only for people with pre-existing conditions to use for insurance. This is a problem because high-risk pools were around since before the ACA, and even with this money set aside, people with pre-existing conditions still couldn't afford insurance. On top of this, high-risk pools still have annual and lifetime caps.

individual insurance

Individual insurance is when one person, a family, or a small business buys insurance by themselves.

individual mandate

This refers to the Affordable Care Act provision that made it so that by law, everyone has to have health insurance, or else they will pay a fine.

lifetime cap

Before the ACA was passed, insurance companies could stop paying for a person's insurance if that person used too much money, or hit their "cap", for health care over their lifetime.

Medicaid

Medicaid helps low-income people and people with disabilities by giving them health insurance paid for by the U.S. government.

Medicaid expansion

The Affordable Care Act made it so that more people are eligible for Medicaid.

medical underwriting

This refers to the practice of insurance companies looking at someone's medical history and then deciding what price they were going to charge that person for insurance. If an insurance company thought that someone might need to see a doctor often, they could charge that person more money.

Medicare

Medicare is health insurance given to anyone over the age of 65. Some people under age 65 with disabilities can also get Medicare.

Obamacare

See Patient Protections and Affordable Care Act (PPACA).

Patient Protections and Affordable Care Act (PPACA)

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.

pre-existing conditions

People with "pre-existing conditions" are people who were sick or disabled before they tried to buy insurance. Some examples of pre-existing conditions are chronic ear infections, autism, cancer (even if you don't have it anymore), high blood pressure, and allergies. Before the ACA, insurance companies were allowed to refuse to give individual insurance to people with pre-existing conditions.

private health insurance

Insurance companies that are run by companies, and not the U.S. government.

public health insurance

Public health insurance is run by the U.S. government and paid for by taxes.

repeal and delay

A proposed strategy that would repeal the Affordable Care Act without any replacement, and the government will instead put off coming up with a replacement for as long as they can. During this time, certain parts of the ACA may be kept, but the money that funds the Medicaid expansion and tax credits would be taken away, which would make it harder for the government to make sure the rest of the ACA's rules are being followed.

tax credits

The ACA made it so that when someone who makes less than \$47,000 per year buys individual insurance, the government will pay part of the cost. The “tax credit” refers to the government paying for part of your individual insurance cost. Parents and married couples can make more than that and still get help paying for insurance.

universal access

Universal access means that everyone should be able to get insurance. This is different from universal coverage.

universal coverage

Universal coverage is when everyone can get insurance that will actually pay for the health care they need, like Essential Health Benefits. The Affordable Care Act focuses on universal coverage, because it has rules to make sure that everyone can pay the same amounts for the same plans.

Further resources

- <https://obamacare.net/>
- [The White House Blog: An American Life, With and Without the Affordable Care Act](#)
- [ACA Fact Sheet by National Disability Navigator](#)
- [ACA Fact Sheet by The Arc](#)
- [The Affordable Care Act and the I/DD Community](#)