Easy Read Edition

Crisis In Our Communities: Racial Disparities in Community Living

Part 6: Getting Good Health Care
Words to Know for Part 6
Covid-19

Covid-19 is a disease that makes a lot of people very sick. It passes through the air, and people who get very sick need a lot of help breathing.

Crisis standards of care

Crisis standards of care are policies that doctors and hospitals use during emergencies. These policies are about how doctors and hospitals decide who to help when they can’t help everyone.

Discrimination

Discrimination is when someone is treated unfairly because of who they are.
Federal qualified health centers

Federal qualified health centers are health clinics that provide preventive care to underserved communities. They follow rules from the government. In exchange the government helps pay for them. One of those rules is that they help everyone in the community even if they can’t pay.

Health inequity

Health inequity is when some groups of people are less healthy than others because of unfair differences in where and how they live.
The Medicaid coverage gap is a problem with Medicaid that means a lot of people don’t get health care. A law passed in 2010 said that states should give Medicaid to more people. A lot of states decided they didn’t want to. They sued, and the courts said they didn’t have to. This meant that a lot of people should be getting Medicaid but can’t. These people are in the Medicaid coverage gap.

Medically underserved communities are communities that do not have enough health care. Sometimes there aren’t enough doctors and nurses in a community. Sometimes a lot of the community is older and has more health needs. Sometimes a community doesn’t have a lot of money.
Preventive care

Preventive care is health care that keeps us from getting sick. It helps us avoid getting chronic illnesses and helps people who have chronic illnesses stay healthy.

Safety net health systems

Safety net health systems are hospitals that serve a lot of patients from underserved communities. These also rely on government payment. Usually this payment comes from Medicaid.

Social determinants of health

Social determinants of health are the conditions in our lives that affect our health. These conditions are part of every place we live, learn, work, play, and age. They affect our health, ability, and quality of life.
Race and Disability in Long-Term Health

Race has a big effect on our health over our lifetimes.

People of color are at more risk of having chronic illnesses.

Chronic illnesses are illnesses that last a long time and need attention from doctors.

Some chronic illnesses cause disabilities.
Some examples of chronic illnesses are:

- Diabetes
- Heart Disease
- High Blood pressure

Chronic illnesses can make people get sick in other ways.
People with chronic illness are at more risk of dying early.

Having a disability can also have a very big effect on people’s health.

Some disabilities cause illnesses.

And, having a disability can make it harder to:

• make money
• stay safe and healthy in our communities

• see a doctor.

These things can make someone less healthy.

They can put someone at risk of getting chronic illnesses.

These two experiences can overlap.
People of color with disabilities experience both.

They experience the same things other people of color do.

This means they’re at more risk of chronic illnesses.

They also experience the same things other people with disabilities do.

This means their disabilities can cause illnesses.
It means it is harder for them to make money or stay healthy.

People of color with disabilities have health risks from both race and disability at the same time.

But even this isn’t the whole story.

People of color are also more likely to become disabled.
People in all groups become more disabled as we age.

But for people of color, this happens much more.

People of color become even more disabled with age.

As we get older, people of color become disabled more often than white people.
A lot of things people of color experience make us more likely to get sick.

These can include:

- Having less money.
- Having less access to healthy food
- Having less access to healthy and safe housing.
• Having less access to doctors and health care.

• Living and working in places that are less safe.

• Experiencing racism and other sources of stress can make us sicker.

These all put people of color at more risk of chronic illnesses.
These chronic illnesses can then cause disabilities.

Both racial disadvantages and disability also mean that people have less money.

We’re less likely to have secure homes, jobs or schools.

These can cause even more disability over time.
People of color with disabilities experience health problems from disability, and from race.

These problems make each other worse.

They make each other bigger.

This means that people of color with disabilities also experience more problems from their disabilities because of racism.
And they experience more problems from racism because of their disabilities.

Access and Health Disparities

One of the most important types of health care is preventive care.

Preventive care keeps us from getting sick.

It helps us avoid getting chronic illnesses.
It helps people with chronic illnesses stay healthy.

Preventive care is things like:

- Shots to keep you from getting diseases like measles.
- Check ups to see if you have any new problems.
- Tests that look for diseases that are hard to notice, like high blood pressure or cancer.
• Advice from doctors and nurses on how to stay healthy.

A lot of preventive care that people get is from regular checkups.

This is when you see your doctor to make sure everything is okay.

Unless someone has another illness, this usually happens once a year.

When people don’t get preventive care, they are more likely to get sick.
They are more likely to get chronic illnesses.

Some chronic illnesses are hard to notice.

They can get worse before anyone notices them.

People without preventive care can get sick without knowing.

They can have even more health problems from chronic illnesses.
It can cost a lot of money to treat these health problems.

These health problems can also cause disabilities.

This can make it hard to keep enough money to stay safe and healthy in other ways.

But not everyone gets preventive care.
One type of community that has trouble getting preventive care are **medically underserved communities**.

Medically underserved communities are communities that do not have enough health care.

Sometimes there aren’t enough doctors and nurses in a community.

Sometimes a lot of the community is older and has more health needs.
Sometimes a community doesn’t have a lot of money.

This is bad for their health.

Sometimes we know a community is medically underserved because we can see bad things happening to their health.

For example if a lot of babies die when they are born it means a community is medically underserved.
If a lot of parents die when they are giving birth, that also means a community is medically underserved.

Usually, the government calls communities medically underserved based on the places those communities are in.

A lot of times communities are underserved because of unfair differences in the places they live.

For example, there was a long time when banks and governments wouldn’t lend money to communities of color.
This made it hard for people to open businesses, including doctor’s offices.

This means a lot of communities of color today are in places that don’t have many doctors.

Communities can also have problems if the government wasn’t doing what it was supposed to.

For example, the government is supposed to give health care to American Indian communities.
But it doesn’t spend enough money on health care for these communities.

It hasn’t spent enough money for a long time.

This means people in these communities have worse health than the rest of America.

But not everyone who is medically underserved lives in the same place.
If the government only calls communities medically underserved because of where they are, the government will miss people.

People who don’t speak English or don’t have legal citizenship can have trouble getting health care.

They don’t always all live in the same place.

They might not get noticed if they don’t.
People with disabilities can get missed when we live in the community.

People with disabilities can have problems getting good health care.

But the problem might not get noticed at all unless we all live together in one place.

But we also have a right to live in the communities we choose.

We should be able to have our problems noticed even if we don’t all live in the same place.
Discrimination in Health Care

Even when we can get health care there are other problems.

Sometimes the health care we get is not very good.

A lot of times, people of color and people with disabilities are not treated as well by doctors.

A lot of times we experience discrimination.
**Discrimination** is when people are treated unfairly because of who they are.

Doctors might have different opinions about people because of a group we are a part of.

They might make different decisions about people because of a group we are part of.

People with disabilities and people of color both experience discrimination in health care.
People of color with disabilities experience discrimination for both race and disability.

They can also have worse discrimination because of both together.

A lot of doctors believe the lives of people with disabilities aren't as good as people without disabilities.

This can mean they think helping people with disabilities is less important.
This can happen even when people with disabilities have health problems that aren’t related to their disability.

Sometimes this type of discrimination is done with policies.

For example, during emergencies doctors sometimes can’t help everyone.

They might not have enough doctors or nurses.

They might not have enough supplies.
They might not have enough time.

They have to make decisions about who to help and how much to do.

Doctors and hospitals use **crisis standards of care** to make these decisions.

Crisis standards of care are policies on how to make decisions during emergencies.
These decisions are hard to make.

They mean deciding to let some people get hurt.

But that doesn’t make it okay to discriminate.

These policies are supposed to make these decisions fairer.

But instead they often discriminate against us.
Crisis standards of care policies often decide people with disabilities are less important to help.

They decide that people with disabilities shouldn’t get help in emergencies.

They do this even when it isn’t harder to help us.

This happened during COVID-19 in 2020.
COVID-19 is a disease that made a lot of people very sick.

It passed through the air.

People who got very sick needed a lot of help breathing.

A lot of hospitals couldn’t help everyone who was sick.
Some hospitals decided not to treat people with disabilities.

They refused to help people with disabilities who came to them.

Sometimes they sent people with disabilities who were already in the hospital home.

Some people with disabilities got sicker and died because they weren’t helped.
Sometimes discrimination is hard to spot

Sometimes people don’t even know they’re discriminating.

They might treat people differently but not know they are doing it.

Or they might treat people differently but think it isn’t unfair.

People with disabilities and people of color experience this type of discrimination too.
We are not treated the same as other patients.

We are often treated worse.

Examples of unfair treatment changing the care we get include:

Assuming that we don’t understand our health

Assuming that we aren’t giving correct information.
Assuming that we can’t make decisions for ourselves

Assuming that we aren’t able to tell people what we need

Thinking that we are being difficult patients when we do tell doctors what we need.

Believing that we don’t need some types of care, like medicine for pain.
Believing that we can’t be trusted with some types of care, like medicine for pain or mental health.

If we don’t communicate by speaking we can have even more problems.

If we don’t speak English, we can have even more problems.

It becomes easier for doctors to ignore what we need.
It becomes easier for doctors to treat us unfairly.

What can we do?

Address Health Disparities Caused By Race and Place

The conditions around us can affect our health in big ways.

These conditions are part of every place we live, learn, work, play, and age.

They affect our health, ability, and quality of life.
These conditions are called social determinants of health.

They can include:

• How much money we have and how much we can rely on it

• How much access we have to school and how good it is

• How reliable and good our homes are
• How safe and healthy our neighborhoods are

• Our relationships with other people and our community.

Being able to be in our communities is important for our health.

Being able to have control over our lives is important for our health.
It is important that we have accessible ways to move around our communities safely.

It is important that we can choose jobs in our communities that fit our interests and skills.

It is important that we can make friends and have fun in our communities.

All of these things also impact our health.
We should make sure that all communities are safe and accessible for us.

We should make sure that every community has good schools and good housing.

We should make sure every community has safe, healthy and accessible things to do for fun.

All of these things have a big effect on our health.
They have a big effect on our ability to stay healthy in the community.

Not all communities have these things.

When communities don’t we should spend more money in those communities.

We should help them build the things they need for healthier communities.
Disabled people of color are at risk of worse health.

A lot of communities of color have less of what we need to stay healthy.

In a lot of these communities it is hard for us to get health care.

This makes other health risks from social determinants of health worse.
Without health care it is hard to get preventive care.

It is harder to avoid chronic illnesses.

It is harder to keep chronic illnesses from causing new health problems.

We need to make sure we know when communities are medically underserved.

We should think of ways to find underserved communities besides the places they are.
We should look at the health experiences of all groups of people in a place.

We need to make sure we’re not missing health inequalities.

We think about people with disabilities as a medically underserved population.

The government should say that people with disabilities are a medically underserved population.
We should think about how disability makes it harder to get health care.

Many people with disabilities have more health needs than nondisabled people.

But we also have a harder time getting the health care we need.

Many of us have other health risks because of racism.

Many of us have chronic illnesses we have trouble getting care for.
Many of us have disabilities caused by chronic illnesses.

Many of us are part of other medically underserved communities.

But we might have other needs too.

When we support medically underserved communities, we should pay attention to the needs of people with disabilities.
We should also find better ways for the government to look at medically underserved communities.

The government should look for ways to find medically underserved communities.

They should look for ways that don’t rely on everyone who is medically underserved living together.

We should also support doctors and hospitals in underserved communities.
Some doctors and hospitals serve these communities in particular.

They need more support.

**Federally qualified health centers** are health clinics that provide preventive care to underserved communities.

1. They follow rules from the government.

2. In exchange the government helps pay for them.
One of those rules is that they help everyone in the community even if they can’t pay.

Almost 1 in 10 Americans get care from a federally qualified health center.

We need to make sure they have enough money to serve these communities.

We also need to keep making more of them.

We need to have them in more places.
Another way underserved communities get health care are called “safety-net” health systems.

These are hospitals that serve a lot of patients from underserved communities.

These also rely on government payment.

Usually this payment comes from Medicaid.

Medicaid doesn’t pay doctors or hospitals as much as other insurance.
This means safety net health systems don’t make as much money.

Recently the government changed how it pays these health systems.

They made changes assuming more people would be getting health care.

They stopped giving health systems extra money for helping people who couldn’t pay.
This means that these health systems get paid less for helping communities that can’t pay.

These changes made it harder for them to stay open.

A lot of safety-net health systems have closed.

A lot of underserved communities lost the main place they could get health care.
It is important to make sure that communities who lost health care still see doctors.

It isn’t enough just to bring safety-net systems back, though.

Safety net systems aren’t enough to stay healthy.

Safety net systems don’t do a lot of preventive care.
Underserved communities used safety net systems because there wasn’t much else.

We should make sure that people have access to care in their communities.

We should do more to encourage doctors to work in communities with a lot of need.

Make Health Care Accessible.

It isn’t enough for health care to be available.
We need to be able to use it.

Our health care needs to be accessible.

People with disabilities need to be able to communicate and be understood.

Doctors need to pay attention to what we are telling them we need.

This is important for us to be able to participate in our care.
This means we should have supports for our disabilities.

If we use a machine to talk for us, doctors need to be able to understand this.

They shouldn’t take these things away from us.

They should listen to what we say we need and don’t need.

They should allow us to make decisions about our health.
Doctors should also make sure they are responding in an accessible way.

If there is information we need, we should get it in ways we can understand.

This may mean that doctors need to give information to us in different ways.

Make Health Care Affordable

One of the biggest problems with getting health care is being able to pay for it.
A lot of people of color have trouble getting health care they can afford.

A lot of people with disabilities also have trouble getting health care they can afford.

People with disabilities are more likely to have health insurance than people without disabilities.

This is mostly because a lot of people with disabilities can get Medicaid.
But people with disabilities also often have more serious health needs.

And not all people with disabilities can get Medicaid.

People with disabilities that can’t get Medicaid have a hard time getting other health insurance.

People with disabilities who don’t have insurance are at even more health risk.
They have trouble paying for preventive care.

This can make their health worse.

We need to do more to make health care affordable.

We need to make sure more people have health insurance.

In 2012 the government passed the Affordable Care Act.
The Affordable Care Act is also called Obamacare.

The purpose of the Affordable Care Act was to make sure that everyone could have insurance.

One way it does this is by making a way that everyone can buy insurance.

But a lot of people still can’t afford insurance.

People who are not legal residents weren’t allowed to use the Affordable Care Act to buy health care.
They can’t even use it if they pay for everything themselves.

This means they have a harder time getting health care.

This makes it harder to get preventive care.

This makes it harder to stay healthy.

People who are not legal residents often have jobs that are less safe.
They make less money.

They usually don’t have housing that is as safe.

All these things mean that they are at risk of having more health problems.

If they also can’t use health care to stay healthy, that can be a big problem for them.
We should change the law to let everyone use the Affordable Care Act to buy health insurance.

Another way the Affordable Care Act helps people get health care is by expanding Medicaid.

The Affordable Care Act said that states should give Medicaid to more people.

It said that Medicaid had to help people get more types of health care.
It said that it would help the states pay for giving Medicaid to more people.

Some states didn’t want to give Medicaid to more people anyway.

They sued to get rid of the Affordable Care Act.

Courts said the Affordable Care Act could stay but it couldn’t make states expand Medicaid if they didn’t want to.
So a lot of states decided not to.

Today, 12 states do not have Medicaid expansion.

In these states a lot of people can’t afford to buy insurance.

A lot of the people who can’t afford insurance still make too much money to get Medicaid.

These people still do not make enough money to be safe and healthy.
They would get Medicaid if the states gave it to more people.

These people are in what is called the **Medicaid Coverage Gap**.

Most of the people who don’t have insurance right now are people of color.

A lot of this is because of the Medicaid coverage gap.

The states that decided not to expand Medicaid have a lot of people of color without much money.
Some of these states also made it even harder to get Medicaid.

If these states give Medicaid to more people they can help these people stay healthy.

The government can try to get states to expand Medicaid by helping to pay even more.

But a lot of states probably won’t want to.
So the government will have to find other ways to help people in the Medicaid Coverage Gap.

They should also make a plan that lets people in the coverage gap get health care.

The government could make a new plan like Medicaid for people in the coverage gap.

It could give everyone the option of using that plan if they can’t get Medicaid.
This would let the federal government help people that the states don’t want to help.

Stop Discrimination in Medical Decisions

Discrimination makes it hard to get good health care.

It’s important to get good health care.

But discrimination makes it hard.

Hospitals and doctors have policies.
Policies help them make decisions about health care.

Sometimes, the policies are good.

They help us get good health care.

Sometimes, the policies are bad.

They discriminate against people with disabilities.
They discriminate against people of color.

Hospitals and doctors should make sure their policies don’t discriminate.

They should include us when they make those policies.

We know a lot about how discrimination happens.

We know how to stop discrimination.
If we are part of making these policies, they are less likely to hurt us.

Hospitals and medical schools often have review boards.

Review boards look at things like new policies.

They look at things like new research.

They make sure new policy or research doesn’t hurt people.
They make sure policy doesn’t discriminate.

They pay attention to how policy or research affects people.

They pay attention to bad effects.

We should make sure that people of color are part of these boards.
We should make sure people with disabilities are part of these boards.

These boards should make sure we can find out how to be a part of these boards.

They should be accessible.

It is important that we are there.

It is important that people who know our experiences are there.
We should also make sure that there are more doctors of color.

We should make sure there are more doctors with disabilities.

If there are more doctors with our experiences, there will be less discrimination.

In order to be a doctor, you need to go to medical school.

But medical school is not very diverse.
There are not many people of color in medical school.

In 2019, less than 1 in ten accepted medical students were Black.

There were even fewer Hispanic medical students.

They were closer to 1 in 20.

This is fewer Black and Hispanic students than in recent years.
This is nearly the same number of Black and Hispanic students there were in the 1970's.

Only 3 out of every 100 students is a Black man.

This is about the same number of medical students who were Black men in 1978.

People of color were discriminated against a lot in 1978.
Schools tried to do better for people of color after 1978.

But it is just as hard now for Black and Hispanic people to go to medical school.

We need to do more to help people of color go to school to become doctors.

This isn’t just a problem among new students.

Not many people who teach at medical schools are Black or Hispanic either.
Less than 1 in 25 full-time medical school teachers are Black.

Medical schools need to recruit and accept more students of color.

They need to hire more teachers of color.

The number of doctors with disabilities has improved over recent years.

But the number of doctors of color has not.
We should be able find doctors who share and understand our experiences.

It is important that the people training new doctors understand our experiences too.