



**CENTER FOR
DIGNITY IN
HEALTHCARE FOR
PEOPLE WITH
DISABILITIES**

**Recommendations to Increase
Access in Organ Transplantation:**

Easy Read Version

Recommendations to Increase Access in Organ Transplantation - Easy Read Version

Part I: Introduction



The [Center for Dignity in Healthcare for People with Disabilities](#) wrote this paper.

We wrote it so you know what we want people to do so that people with disabilities can get [transplants](#).

Part I will answer these questions:

- What are transplants?
- Why are transplants important?
- What is the Center for Dignity in Healthcare for People with Disabilities?
- What does the Center for Dignity do?
- Why do people with disabilities have a hard time getting transplants?
- How did the Center for Dignity study transplants?
- How did we fix gaps?
- What is the Americans with Disabilities Act?
- How does the Americans with Disabilities Act get rid of discrimination in transplants?



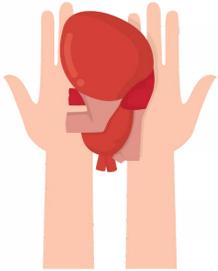
What Is A Transplant?



A [transplant](#) is when a doctor takes a body part from one person. They put the body part in a different person.

An **organ** is a really important body part.

A heart is an organ.



The person who gives another person their organ is a **donor**. Sometimes the transplant happens after the donor is dead. Sometimes the transplant happens when the donor is alive.

Different organs have different rules. The rules are about when you can transplant the organ. Doctors know these rules.



Why are transplants important?

People need organs to live. When an organ stops working, you need a new one.

For example:

Jodie's heart stops working. Jodie needs a transplant.

Jodie needs doctors to take her heart out. Then the doctors put a working heart inside her.

If Jodie does not get a transplant, Jodie will die.



This is what happens to all people who do not get transplants they need.

That is why transplants are so important.

We want everyone to get a transplant who needs one.

What is the Center for Dignity in Healthcare for People with Disabilities?



The Center for Dignity in Healthcare for People with Disabilities is a coalition.

We will call it the Center for Dignity.

A coalition is a group of people who know a lot about something.

The group comes together to work on the thing they know about. Our coalition is made up of:

- doctors
- scientists
- people with disabilities
- Family members of people with disabilities
- ethicists



Ethicists are people who think about what is right and wrong for a living.

This is not what is true or false.

It is what you should do or not do to be fair.

This helps other people decide what is right and wrong.

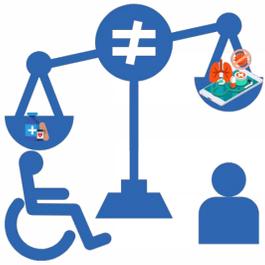
What does Center for Dignity do?

Our coalition works on health care.



We want to help people with disabilities get the same health care as everyone else.

Sometimes, people with disabilities do not get the same health care as everyone else.



This is called a health care inequity.

An inequity means something is not equal. It means something is not fair.

Health care for people with disabilities is not equal and not fair right now.

Sometimes when people do not get the same health care, it is because of **discrimination**.



Discrimination is treating someone or a group of people differently because of who they are.

We believe there should not be discrimination in health care.

We work mostly for people with intellectual and developmental disabilities (I/DD).

We will call them people with I/DD.

People with I/DD have a disability as soon as they are born.

That disability makes them think differently than other people.



It can make some things harder. It can make some things easier. There are lots of different kinds of I/DD.

Some kinds of I/DD are:

- Autism
 - Cerebral Palsy
 - Down's Syndrome
 - Williams Syndrome
 - Attention Deficit Disorder (ADD)
- ...and many more!



People with I/DD have the same rights as everyone else.

But, sometimes people do not give people with I/DD all their rights.

This happens a lot in health care. It happens with transplants.

Our coalition looks at discrimination in health care for people with I/DD.

We find out why it happens.

We help people with I/DD and their families fight discrimination.



We help make sure doctors know about people with I/DD and discrimination.

We help doctors know how much good health care improves peoples' lives.

We also help doctors understand how not to discriminate against people with I/DD.



Sometimes we do this by creating papers called [recommendations](#).

Recommendations tell people how they should do something.

We also help people find and create guidelines.



[Guidelines](#) are rules that people follow.

The guidelines we find help people not discriminate.

The recommendations help people learn how not to discriminate.

Sometimes, we look at guidelines people already have.



We find places where the guidelines do not stop discrimination.

These places are a kind of **gap**.

A **gap** is a place in laws or rules where discrimination is not stopped.

There are also gaps in what people know. These gaps make them **discriminate** more often.

Finding gaps is very important if you want to make sure discrimination does not happen.

Sometimes there are things in the world that stop other people from giving people with disabilities what they need.



These are called **barriers**.

Our recommendations help doctors get rid of barriers.

This is what the Center for Dignity does.

We made recommendations in this paper for getting people with I/DD transplants.

Why do people with disabilities have a hard time getting transplants?

We think it is hard because of **implicit bias** and **explicit discrimination**.

These things are caused by **prejudice** and **stereotypes**.

Some people have **prejudice** against people with disabilities.



Prejudice is when you believe something bad about another person because of who they are.

Sometimes prejudice makes it hard for people to get organ transplants.



For example:

Shuchang has a disability.

One day, Shuchang's lungs stop working.

Shuchang goes to the doctor.

Shuchang tells the doctor that he needs a new lung.

There are not that many lungs.



The doctor tells Shuchang that he will not give him a lung.

The doctor will not do this because he thinks people with disabilities live worse lives.

This is a kind of prejudice.

Denying someone services because they have a disability is discrimination.



It is treating someone differently because of who they are.

This kind of discrimination is **explicit** discrimination.

Explicit means it is on purpose. The person knows about it.

But sometimes, the person does not know that they are treating people differently.

This kind of discrimination is different from the kind the person knows about.

It is the kind where they do not know about it.

It is implicit bias.

Bias is another word for prejudice. Bias causes discrimination.



Bias can also mean that you believe stereotypes.

Stereotypes are a kind of idea about a group of people. The idea is that everyone in the group is the same.

Stereotypes can hurt people.

Sometimes stereotypes hurt people even when the person who believes them does not know they do.

Doctors have a lot of implicit bias.

They might make lots of decisions because they have prejudice against people with disabilities.

They might make lots of decisions because they believe a stereotype.

They might not know they believe the stereotype.

They act on it anyway.

Implicit bias and explicit discrimination are both bad.

They both make it hard for people with disabilities to get transplants.



It is also hard for people with disabilities to get transplants because they do not always get [accommodations](#).

Accommodations are changes that help people with disabilities get the same services as others.

Sometimes doctors do not give people with disabilities accommodations for transplants. This is discrimination.

The Center for Dignity helps doctors learn about disability discrimination.

We help doctors learn about implicit bias and explicit discrimination.



If doctors know they have these wrong beliefs, they might change what they do.

These changes help them treat people with disabilities better.

How Did the Center For Dignity Study Transplants?

We wrote a paper about it.

We call this paper a [gap analysis](#).

A gap analysis is a kind of [research paper](#).

A research paper is a paper where:

- A group of people try to find out something true.
- The people find out what they think is true by studying it.
- The people write down what they found out.





A research paper is just what the writers think is true. Sometimes the writers are wrong.

But the writers have good reasons for thinking the paper is true.

They have **evidence**.

Evidence are facts that show something is true.

You get evidence from studying something.

Good evidence means it is more likely that the writers are right. Good evidence makes research papers better.

People who write research papers are often scientists.

They do not have to be.

The Center for Dignity is made up of scientists.

It is also made up of other people who know a lot about disability.

A gap analysis is a research paper where people try to find out how to fix a problem.

There are things you have to do in a gap analysis.

You have to figure out what is causing the problem right now.

Our problem was transplants and people with disabilities.

People with disabilities were not getting transplants as often.

The Center for Dignity studied the problem to find out why.

You have to figure out what you want to happen instead.





The Center for Dignity wants everyone to get a transplant who needs one.

You have to figure out why the right thing is not happening.

The writers of a gap analysis do this by finding **gaps**.

A gap can be in:

- The laws
- The rules
- The things people know

You have make a plan to get rid of the gaps.

Our gap analysis did this.

How Did We Fix Gaps?

We decided that one way to get rid of the gaps was by making recommendations.

Recommendations tell people how they should do something.

We want to make sure doctors know about people with disabilities and discrimination.

We also want to help them learn how to not discriminate.

We wanted to help other people stop discrimination when it happens.

We wanted to help make better rules and laws about transplants.

Our recommendations tell people how to do all these things.



Following our recommendations will help people with disabilities get transplants.



What is the Americans with Disabilities Act?

A lot of our recommendations have to do with a law.

The law is about the rights of people with disabilities.

This law is called the [Americans with Disabilities Act](#).

The Americans with Disabilities Act passed in 1990.

It was made to get rid of many different kinds of discrimination.

Some kinds of discrimination are part of the way a [community](#) works.

A community is a place where people live.

The Americans with Disabilities Act helps to get rid of this kind of discrimination.

How does the Americans with Disabilities act get rid of discrimination in transplants?

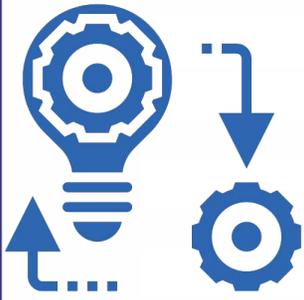
One way to fix it is by giving everyone [accommodations](#).

The Americans with Disabilities Act says that doctors have to give people accommodations.

They have to give people accommodations when they are doing organ transplants.

The Americans with Disabilities Act says that doctors have to change the rules they follow.





They have to change the rules if people with disabilities need the changes to get health care.

These changes are modifications.

Doctors can change the rules when someone gets a transplant.

For example:

After you get a transplant, you have to do a lot of different things. You have to do these things to keep your new body part working. If you do not do these things, the body part stops working.



These things you have to do are post-operative care.

Doctors follow rules about who gets a transplant.

Sometimes the rules say that you have to do post-operative care without help.

If you need help, you do not get a transplant.

This discriminates against people with disabilities.

They sometimes need help.

Doctors could fix this by making a modification.

This means changing the rule.

The rule would say something different.

It would say that people who need help could still get an organ.



We found that doctors do not always give people accommodations.

Doctors do not always give people enough accommodations.

Doctors do not always make the right changes to their rules.

The Center for Dignity thinks that this is bad.

We think it is against the law.

We think it is against the Americans with Disabilities Act.

A lot of our recommendations are about making sure doctors follow the Americans with Disabilities Act.



Doctors can do this by giving people what they need to get transplants.

They can do this by giving people with disabilities transplants as often as people without disabilities.

Our recommendations are in the parts of this paper that come next.

Transparency and Oversight of Selection Criteria for Organ Allocation



In Part II we will answer these questions:

- What does the Title mean?
- What are Organ Transplant Centers?
- How do Organ Transplant Centers get people transplants?

- How can Organ Transplant Centers make better transplant rules?
- How should Organ Transplant Centers show people what the rules are?

What Does the Title Mean?

The title says what the recommendations under it are for.

We will talk about what the words in the title mean so you can understand it.



Transparency is a word that means that everyone can see and understand something.

When people can't see or understand something, it is opaque.

The Center for Dignity in Healthcare wants decisions about who gets transplants to be transparent.

That means we want everyone to understand how doctors make decisions.

Right now, these decisions are hidden.

No one knows about how they are made other than doctors.

The decisions are opaque.

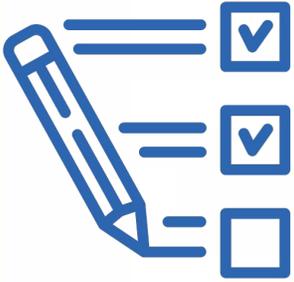
Oversight is a word that means that there are people who make sure that something is done right.



Sometimes if no one looks at something being done, it gets done wrong.

We want more people to have oversight over organ transplants.

Selection Criteria is two words.



A criteria is a list or paper that says how a decision is made.

For example:

A criteria for going in the pool during adult swim is that you have to be an adult.

Kids do not meet this criteria for going in the pool.

We will usually use “transplant rules” to mean criteria.

Selection means choosing between more than one thing.

Doctors choose between people when they are figuring out who will get an organ.



So “Selection Criteria” means a list or paper that shows how people should decide between more than one thing.

Allocation is a word which means deciding who gets

something. So organ allocation means deciding who gets an organ.

The title of this part says what we made recommendations about.

When you take all these words in the title together, it means that this Part is about:

- Making sure that doctors make decisions about transplants that everyone can see and understand.
- Making sure that more people are looking at how doctors make decisions about organs.

What are Organ Transplant Centers?



If you want to get an organ, you have to get surgery.

Surgery is where a doctor opens up your body.

The doctor does something to the inside of you.

You can only do some kinds of health care with surgery.

A transplant opens up your body and puts a working body part inside it.

Transplants can only be done with surgery.



An Organ Transplant Center is where a person has the surgery to get an organ.

Organ Transplant Centers decide who gets an organ transplant.

How Do Organ Transplant Centers Get People Transplants?

OPTN

They do this by telling a group that they want to do the transplant. That group is the Organ Procurement and Transplantation Network. We will call them OPTN.



The OPTN has group members, but it is run by [The United Network for Organ Sharing](#).

The United Network for Organ Sharing makes transplant rules for the entire United States.

It helps Organ Transplant Centers do organ transplants.

It helps doctors get organs to transplant.

When an Organ Transplant Center tells OPTN they want to do a transplant, OPTN puts the name of the person on a list.

This list is a [waiting list](#).

People on the list wait for their turn to get a transplant.

Sometimes, Organ Transplant Centers discriminate against people with disabilities.

This means that they do not put people with disabilities on the waiting list as often.

Sometimes Organ Transplant Centers discriminate because of the rules they follow.

The Center for Dignity studied Organ Transplant Centers.

We think that there are things they can do to make better rules.



What Can Organ Transplant Centers Do To Make Better Rules?

Organ Transplant Centers should talk to people with disabilities.

They should talk to them about their transplant rules.

They should talk to them about making better transplant rules.

They could also talk to family members of people with disabilities.

Organ Transplant Centers should write their transplant rules with people with disabilities helping.

Family members should also help write the transplant rules.

People with disabilities and their families know the most about disability.

They can come up with ideas that other people would not have.

They may have new ideas because of some part of who they

are. Examples of parts of who you are:

- Whether you are a person of color
- How much money you have
- How old you are
- Where you live

They may have new ideas because of their disability.

Organ Transplant Centers should listen to these ideas.



Organ Transplant Centers should also listen to the United Network for Organ Sharing.

The United Network for Organ Sharing wrote papers.

The papers were on how to give out organs in an ethical way.

Ethical means the right or wrong way to do something.



This does not mean whether it is true or false.

It means whether it is fair or not fair.

Organ Transplant Centers could look at these papers.

They could ask the United Network for Organ Sharing what is ethical.

The United Network for Organ Sharing could tell them how to make the rules for getting transplants fair.

Then Organ Transplant Centers could make the rules fair for people with disabilities.

How Should Organ Transplant Centers Show People What the Rules Are?



All transplant rules should be written on the Organ Transplant Center's website.

Anyone should be able to get to the rules.

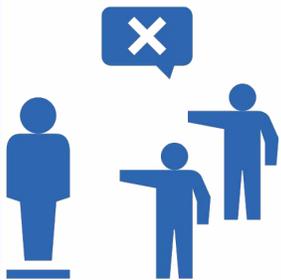
The website should not make it hard.

Organ Transplant Centers do not always have the transplant rules where everyone can read them.

This means that they can discriminate without anyone ever knowing about it.

It means some Organ Transplant Centers have written rules that discriminate against people with disabilities.

This is because no one could see them.



Some Organ Transplant Centers do not have the rules written down.

The rules they do have are not clear.

Sometimes if the rules are not clear, people will discriminate.

If the rules are on the website for anyone to read, these problems do not happen.

That is why we think Organ Transplant Centers should write down the rules where everyone can see them.

Part III: Person Centered Planning and Supported Decision-Making

In Part III we will answer these questions:



- What is person centered care?
- What is person centered planning?
- What is guardianship?
- What is supported decision-making?
- How can doctors who do transplants do supported decision-making better?
- How do person-centered planning and supported decision-making make organ transplants better?

What is person centered care?

Person centered care means that the doctor does health care based on what the person needs and wants from their own health care.



In most health care, the doctor tells the person what the doctor will do.

The person says “Yes” or “No” to what the doctor says.

Person centered care is different.

The doctor looks at how the person is feeling.

The doctor asks the person what they want from health care.

Some things people might want from their health care:

- To feel better
- To have a plan for feeling better
- To get something done that helps them
- To be respected
- To make choices about what happens to them



The doctor asks the person how they want to get there.

Then the doctor creates a plan to get the person what they need.

The doctor gives the person what they need to understand health care.

Then the person knows how to help the doctor make choices.

The doctor gets help from the person's family and friends.



The doctor makes it easier for the person to meet with them.

The doctor respects what the person believes.

The doctor respects the person's culture.

By taking these steps, the doctor gets help from the person.

The doctor makes better choices.

The person understands their health care.

If the doctor and the patient work together, the health care is better.



The doctor knows more about the person.

The doctor makes better choices.

The person knows more about why the doctor is asking them to do something.

People who use patient centered care are in better health.

They are happier with their health care.

This is why person centered care is important.

What is person-centered planning?

[Person-centered planning](#) is where a doctor and a person make choices about the person's health care together.



It can be a big part of person-centered care.

Just like in person-centered care, the doctors mostly try to do what the person wants from their health care.

In person centered planning, doctors look more at what the person can do than at what they can't do.

This is called looking at the strengths of the person. Sometimes people call it a [strengths-based approach](#).

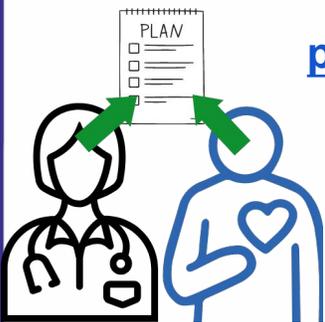
Person-centered planning can be done in lots of different ways.

When person-centered planning is done right, it makes people's health better than if it was not used.

The doctor and the person often create a

[person-centered plan](#). This is a paper that says:

- What the person wants to happen
- What the best way is to do it
- Who will make sure the person gets what they want



A good person-centered plan in health care is often written down. This makes sure doctors follow it.

The person centered-plan is often made by the person's [circle of support](#).

A circle of support is a whole group of people who help the person with a disability make choices.

They also help the doctor understand what the person wants from their health care.

The members of a circle of support are often:

- a person with a disability
- their family
- sometimes the people who help them with daily life, called their [caregivers](#);
- close friends.



Following the plan helps doctors make a person get better health care.

We think everyone should use person-centered planning.

What is guardianship?

We think people should do person-centered planning no matter what.

We think it should happen with organ transplants.

It helps doctors understand what people need from health care.

Sometimes, though, people with disabilities do not have the right to make choices.

When this happens, doctors have to talk to the person's guardian too.



Guardianship is where someone gets the right to make choices for someone else.

The person who makes the choices is called a guardian.

Most children have guardians.

Adults who have guardians are always people with disabilities.

For someone to get a guardianship over an adult, they have to go to court.

The court decides whether the person with a disability needs a guardianship.



Sometimes the court gives the guardian power over every choice.

Sometimes the court gives the guardian power only over some choices.

Guardianship takes away most of your rights.

A person who has a guardian often can't:

- Buy a house
- Make choices about money
- Make choices about health care
- Make choices about who to live with

But if a person has a guardian, the doctors have to talk to the guardian.

The guardian makes the final choice about the person's health care.



What is supported decision-making?

The Center for Dignity does not think guardianship should happen very often.

We do not think it is needed very often.

A lot of people think that guardians are always needed.

These people think that a person with a disability cannot make choices.

We know this is not true.

We think people should mostly use supported decision-making instead.

Supported decision means that a person with a disability makes their own choices.

The person with a disability gets help from a support person or group of support people.

A support person or support people talk to the person about the choice they are making.

They help the person understand the choice.

The person still makes the choice themselves.

In supported decision-making, a person with a disability mostly does not have a guardian.

The person with a disability has the right to make choices about health care instead.

This method helps people with disabilities do self-advocacy.





Self-advocacy is when a person is able to tell other people what they need.

They can fight for their own rights.

Supported decision-making also helps with person-centered planning.

It also helps with person-centered care.

What the person wants from health care is more clear when they make all choices.

The [National Resource Center for Supported Decision-making](#) is a group that works on supported decision-making and guardianship.

They also think supported decision-making should be used instead of guardianship.

How can doctors who do transplants do supported decision-making better?



We think that doctors should let the person's support people come to the doctor with them.

We think doctors who do organ transplants should let the support people come too.

The person's support people help the person decide what to do.

The doctor should treat the person with a disability as the person who makes the choice.

They should do that even though there are support people there. The support people do not make choices for the person.

They just help the person understand what is going on.

For example:

Khalique needs a transplant.



One of his organs, called a kidney, stopped working.

Khalique uses supported decision-making.

His friend Jackie helps him make decisions. So does his friend Jaden.

Khalique brings Jackie and Jaden to the doctor with him.

The doctor is at an organ transplant center.

That is the place where they do transplants.

The doctor tells Khalique what he has to do to get a new kidney.

Khalique has trouble figuring out what the doctor is saying.

Jaden understands the doctor.

He tells Khalique what the doctor means.

Khalique is still worried.

He doesn't know if he can do what the doctor said.

Jackie says she knows how Khalique could do it.

Khalique listens to Jackie explain.

He smiles. He thinks she is right.

He tells the doctor he can get the kidney transplant.

Khalique made the choice.



How can person-centered planning and supported decision-making make organ transplants better?

There are a couple more ways that these two ideas can help.

One way is with better accommodations.



Accommodations are changes that help people with disabilities get the same services as others.

Making it easier for people to take the right medicine is one good accommodation.

Taking the right medicine is really important for transplants.

You have to do it after you get a new organ.



If you don't take the right medicine, your new organ could stop working.

If you don't take medicine at the right time, your new organ could stop working.

It is hard for everyone to take the right medication.

People without disabilities have trouble.

People with disabilities can take the right medicine with

support. That support might be [accommodations](#).



One accommodation might be alarms. The alarms tell you when to take medicine by making a noise.

Another accommodation might be an [app](#). An app is a program on a computer.

You can ask your doctor, friends, or family about the different apps there are.

Another accommodation is pill organizers.



These are boxes that let you match medicine to dates and times.

All of these accommodations help people not make mistakes with their medicine.



Medicine mistakes are the biggest reason people are put back into the hospital after they get a transplant.

You can use person-centered planning to make accommodations.

Your [circle of support](#) can decide that you need help taking your medicine.

They can come up with these medications with you.

This is even easier if you are using [supported decision-making](#).

You can choose which accommodations are best.



[Home and Community Based Services \(HCBS\)](#) are another way a person with a disability could get help with transplants.

HCBS are a kind of [Long Term Service and Support \(LTSS\)](#).

LTSS are services that help people with disabilities live their everyday lives. HCBS are those services in the community.



The Autistic Self Advocacy Network says a lot more about HCBS in their toolkit, "[This Rule Rules!: The HCBS Settings Rule and You.](#)"



HCBS can be used in the person-centered planning process as a way to get people what they need for health care.

This is because they can pay for people who help people with disabilities use accommodations.

A hospital should also provide good training to the person and their family or caregivers.

They should do this before the person leaves the hospital.

This training should include other ways a person needs to care for themselves after a transplant surgery.

This training will also help people with disabilities and their families know when they should call the doctor.

You can teach a person's support people through the training.

They can then teach the person with a disability.

This will help people with disabilities have better transplants.

Part IV: Disability and Diagnosis Related Criteria for Transplants:



- What is a diagnosis? What are “diagnosis related criteria?”
- What does the Center for Dignity believe about who should get organ transplants?
- What is quality of life?
- Why does it cause discrimination?
- What are some other kinds of discrimination?
- What should doctors do to not discriminate?
- What does the Americans with Disabilities Act say about transplant discrimination?
- What do doctors say about why people with disabilities should not get organ transplants?
- Why are the doctors wrong?
- Why should people with disabilities get organ transplants?
- What if a person really can't have a transplant?
- What else has the National Council on Disability said about organ transplants?
- Have doctors fixed any of these problems?



What is a diagnosis? What are “diagnosis related criteria?”

A [diagnosis](#) is another word for a disability or health problem.

Diabetes is a diagnosis. Cerebral palsy is a diagnosis.



A [criteria](#) is a list or paper that says how a decision is made.

“Diagnosis related criteria” would be a list about what a diagnosis has to do with a choice.

In this paper, it means a list or paper about how and whether disability should change who gets a transplant.

That is what the recommendations in Part IV are about.

What does the Center for Dignity believe about who should get organ transplants?



We agree with the [National Council on Disability](#).

The National Council on Disability is an [agency](#).

An agency is a part of the United States government.

Agencies work on different things from one another.

The National Council of Disability helps people with disabilities live better lives.

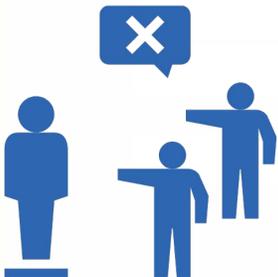
They tell other agencies what those agencies should do to make people with disabilities' lives better.

The National Council on Disability says:

“Subjective judgments about the [quality of life](#) of people with disabilities, made by medical professionals without the input of their patients, have no place in medical decisions. Such judgments often are that people with disabilities, by virtue of being disabled, have a lower quality of life, and that belief, in turn, results in undervaluing their lives.”

This paragraph means a couple different things.

It means that doctors should not judge people with disabilities based on stereotypes.



Stereotypes are a kind of idea about a group of people.

The idea is that everyone in the group is the same.

Stereotypes can cause discrimination.

What is quality of life?

One of the stereotypes doctors have about people with disabilities is about quality of life.



- 10 This is the one the National Council on Disability talked about.
- 5 Quality of life means how good a person's life is.
- 0 Some parts of quality of life have to do with your health.

For example:

If you have a cold, you will feel bad.

Your nose might be stuffy.

You might cough a lot.

These parts of having a cold are not fun.

They might make you feel like your life is worse.

This is why quality of life has to do with your health.

Why does it cause discrimination?

Many doctors think people with disabilities all have worse lives. They think this because there is a stereotype about it.

This is not true.

People with disabilities might have very good lives.

They might be happier than people without disabilities.

They might be in better health.

They might have more family and friends.

It is different between different people.

It does not matter whether they have a disability or not.

Because doctors think people with disabilities have a worse quality of life, sometimes they do not give them transplants.

This is because they think their lives are worth less.

This is discrimination.

What are some other kinds of discrimination?

Sometimes doctors decide people with disabilities should not get transplants because they can't do [post-operative care](#) without help.

Post-operative care are the things you have to do after a transplant to keep your new body part working.

People with disabilities might not be able to do post-operative care without help.

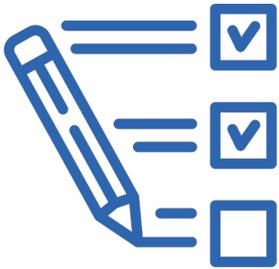
But they can do post-operative care with help.

This is discrimination, too.

What should doctors do to not discriminate?

Sometimes the doctors write down the discrimination in [criteria](#).





Criteria that say these things are discrimination.

They should be changed.

Doctors should not make decisions about people with disabilities unless people with disabilities help make the decision.

Doctors should not decide who gets a transplant without talking to the person who needs it.

We believe doctors must look at each person individually.

This means the doctors just look at the person by themselves.

They also do not look at any stereotypes about disability.

For example:

Matoko needs an organ transplant.

Doctors who do the right thing look at just Matoko.

They do not look at other people with disabilities when they decide things about Matoko.

They do not have stereotypes about how good Matoko's life is.

They do not think that Matoko cannot do post-operative care at all.

They just look at Matoko and his health and decide whether he needs a transplant or not.

They give him any accommodations he needs.



What does the Americans with Disabilities Act say about transplant discrimination?

The [Americans with Disabilities Act](#) is a law that protects the rights of people with disabilities.

The law says that people have to do an *"individualized consideration of disability."*

People includes doctors who do transplants.

This means that people with disabilities have to have their disability looked at individually.

Doctors can't choose to not give someone health care just because of their disability.

They can't choose to not give someone a transplant just because of their disability.

The doctors just have to look at the person and their health.

The doctors have to look at what is known right now about transplants and disability.

They should not be looking at old or bad evidence.

The doctor's choice should not be about stereotypes about disability.

They can't say that a person can't keep their organ working based on stereotypes about their disability.



The [Americans with Disabilities Act](#) also says that doctors have to let people have [accommodations](#).

For example:

Elena got an organ transplant.

Elena can't take her medicine by herself.

Medicine is part of her post-operative care.

Post-operative care is what you need to do to make sure a transplant keeps working.

Elena needs help from her [caregiver](#).

Elena's caregiver helps her do what she has to to take her medicine.

If Elena's doctor said she had to take her medicine without help, this would be against the law.

Sometimes the doctor needs to give the person [accommodations](#). The doctor might have to change how they tell people things. They might have to change how they do things.

They might have to give the person something that helps them.

That is what the Americans with Disabilities Act says.





If the doctor says that a person has to do post-operative care without help, it would be against the law.

What do doctors say about why people with disabilities should not get organ transplants?

Transplant doctors may still say that post-operative care is too hard.

Doctors may say that post-operative care is a big task.

They will say that many people with disabilities can not do it.

Post-operative care happens when the transplant is over.

It is true that it is really hard.

You have to take medicine at the same time every day.

You have to do it for the rest of your life.

You have to see the doctor often.

You have to see the doctor for the rest of your life.

Why are the doctors wrong?

Because the ADA says you do not have to do post-operative care by yourself!

Most people with disabilities can do post-operative care.

They can do it if they have:

- Help from the people who help them with daily life
- Help from friends
- Accommodations, like apps and alarms
- Services and support



Doctors have to think about what support the person has.

Then they have to make the choice about doing a transplant.



Doctors can not look only at what the person can do with no support.

They have to look at what the person with support can do.

If the doctors do not look at the support the person has, it is against the law.

It is against the Americans with Disabilities Act.

This is unfair for people with disabilities.

Why should people with disabilities get organ transplants?



Research papers show that transplants work for people with disabilities.

Transplants work for people with I/DD.

That is the group of people with disabilities the Center for Dignity looks at.

Sometimes research papers are called studies.

Scientists did studies.

The studies looked at how often people with I/DD died after a transplant.

People with I/DD did not die more often than people without disabilities.

People with I/DD were the same.

Other studies looked at **grafts**.

Sometimes only part of an organ stops working.

Doctors do surgery when this happens.

They take out the part that is not working.

They put in a working part instead.

This is a graft.

The studies found that people with I/DD die after grafts just as often as people without disabilities.

Most grafts work for people with I/DD.

People with I/DD have also said that their lives are better after a transplant.

The people who help them do things in daily life also agree.

This means that the transplants make their quality of life better and not worse.

This is good evidence.

The evidence shows that doctors have no reason to discriminate against people with disabilities.

What if a person really can't have a transplant?

Sometimes a disability might really do something to make a transplant not work.



This should not happen very often at all.

For example:

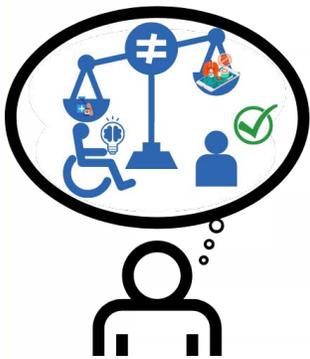
A person could have a rare disease.

That rare disease could make putting new body parts into their body very risky.

The disease makes it so that doing that would kill them. The doctor looks at the person themselves, not at the disease. The doctor chooses to not give the person a transplant. That is because doing a transplant would kill the person.

The doctor would need to be really sure they can't do a transplant.

The doctor should not be making that choice because of prejudice.



The doctor should not be making that choice because they have stereotypes about people with disabilities.

The doctor should check to see whether they have any [implicit biases](#).

They should be really sure they do not have any implicit biases before they choose not to do a transplant.

If a doctor does not know what to do, they should check with other doctors at the hospital.



Other doctors around them might know more about the person's disability.

The other doctors could give them advice.

Doctors who do this before choosing not to transplant will help save lives.

They will help fight stereotypes.



What else has the National Council on Disability said about organ transplants?

In 2019, The National Council on Disability wrote a report about transplants.



Their report had [recommendations](#) in it.

This report was called: **[“Organ Transplant Discrimination Against People with Disabilities.”](#)**

This report has a lot of important things in it.

It tells people all about organ transplant discrimination.

It has not helped the the discrimination stop.



Have doctors fixed any of these problems?

No they have not!

The Organ Procurement and Transplantation Network made a white paper in 2021.

OPTN

The Organ Procurement and Transplantation Network run organ transplants.

A white paper is used to help a group make important choices about an idea.

White papers explain what the group thinks about the idea.

They called the white paper “[General Considerations in Assessment for Transplant Candidacy](#).”

This title means the paper is about how doctors decide who gets a transplant.

The white paper did not talk about any of the things people with disabilities are worried about.

It did not talk about disability discrimination.

These problems are still very important to people with disabilities.

They need to be talked about in papers in the future.



Part V: Data

Part V will answer these questions:

- What is data?
- What kind of data do we need for organ transplants?
- What do we think scientists should do to get the data?
- What else do we need more data on in transplants?
- How do we think scientists should get this data?



What Is Data?

Data is a kind of evidence.



Evidence is a fact that shows that something is true.

Data is evidence that is put together.

Data is mostly evidence that is numbers.

Sometimes data is facts too.

People use data to decide that something is true.

They get a bunch of data and put it together.

Then they decide whether the fact they have data on is true.

Data is very important. Without data, it is hard to show that something is real. People will think a fact is not true if there is no data.

What kind of data do we need for organ transplants?

We have seen discrimination happen in transplants a lot of times.

Sometimes we see discrimination talked about on the news. Sometimes there are court cases about it.

Sometimes doctors even change the rules because of it.
But we still need a lot more data.

We need data about when and how discrimination happens
in transplants.

Sometimes, no one tells anyone else about discrimination
against a person with a disability.

Sometimes discrimination can look like a doctor not caring if
a person with a disability is sick.



Sometimes discrimination can look like a doctor telling the
person there is nothing they can do, when they could do a
transplant.

Sometimes the discrimination is in the rules used by organ
transplant centers.

These rules say that the doctors there can't do transplants
for people with disabilities.

This is explicit discrimination.

But nobody knows about it.

The rules are not out in the open for everyone to read.

They are not transparent.

When discrimination happens this way, it is hard to tell there is discrimination.

We need to know about these rules to stop discrimination.

We need data on how many rules like this there are.

What do we think scientists should do to get the data?

We think they should do a very big study.

The study would look at the rules Organ Transplant Centers have. It would put them out in the open.

That study would show everyone:

- What the rules say
- What kinds of discrimination are in the rules

We think data like that would help people stop transplant discrimination.

It would help governments make rules to stop discrimination.

What else do we need more data on in transplants?

Sometimes a person does not even know they are discriminating against someone.



This is called [implicit bias](#).

Implicit bias can cause people to discriminate.

Most people do not think about people with disabilities very often. They do not look at what kinds of prejudice they have.

They do not look at what stereotypes they think are true.

We think that [implicit bias](#) causes doctors to [discriminate](#) against people with disabilities.

We think that doctors do not give them organs because of [prejudice](#) about disability.

We think that doctors do not give them organs because of [stereotypes](#) about disability.

How do we think scientists should get this data?

No [research](#) has ever been done that shows this.

We think that scientists should do research.

That research should look at what doctors think about people with disabilities.

The research should look at whether what doctors think makes discrimination.

The research should look at how much discrimination the doctors' thoughts make.

That research would be data.

Doctors are trained in **medical schools** and in hospitals.



That data would help **medical schools** and hospitals train doctors better.

It would help medical schools and hospitals choose what to tell the doctors to stop discrimination.

The data would help make organ transplants more fair for people with disabilities.

Part VI: Conclusion

In Part VI we will end our paper. We will answer these questions:



- What do we want doctors to do?
- How can the Center for Dignity help?

What do we want doctors to do?

We are asking doctors to end discrimination against people with disabilities.



We are asking them to end discrimination in organ transplants.

We are asking them to read this paper.

We are asking them to learn from this paper.

How can the Center for Dignity Help?

The Center for Dignity is here to help doctors.

We want to help doctors make our recommendations work.

We will give doctors advice if they ask.

We will tell doctors what they need to know if they ask.

We hope that this paper helps people.



Sources

These are the studies and papers you can read to find out more.

A study is another word for a research paper.

A research paper is a paper where people study something and then write down what they think is true.

Most research papers are not easy to read.

But they are helpful if you can read them.

There are also a couple laws and other papers we used.

They are here too.

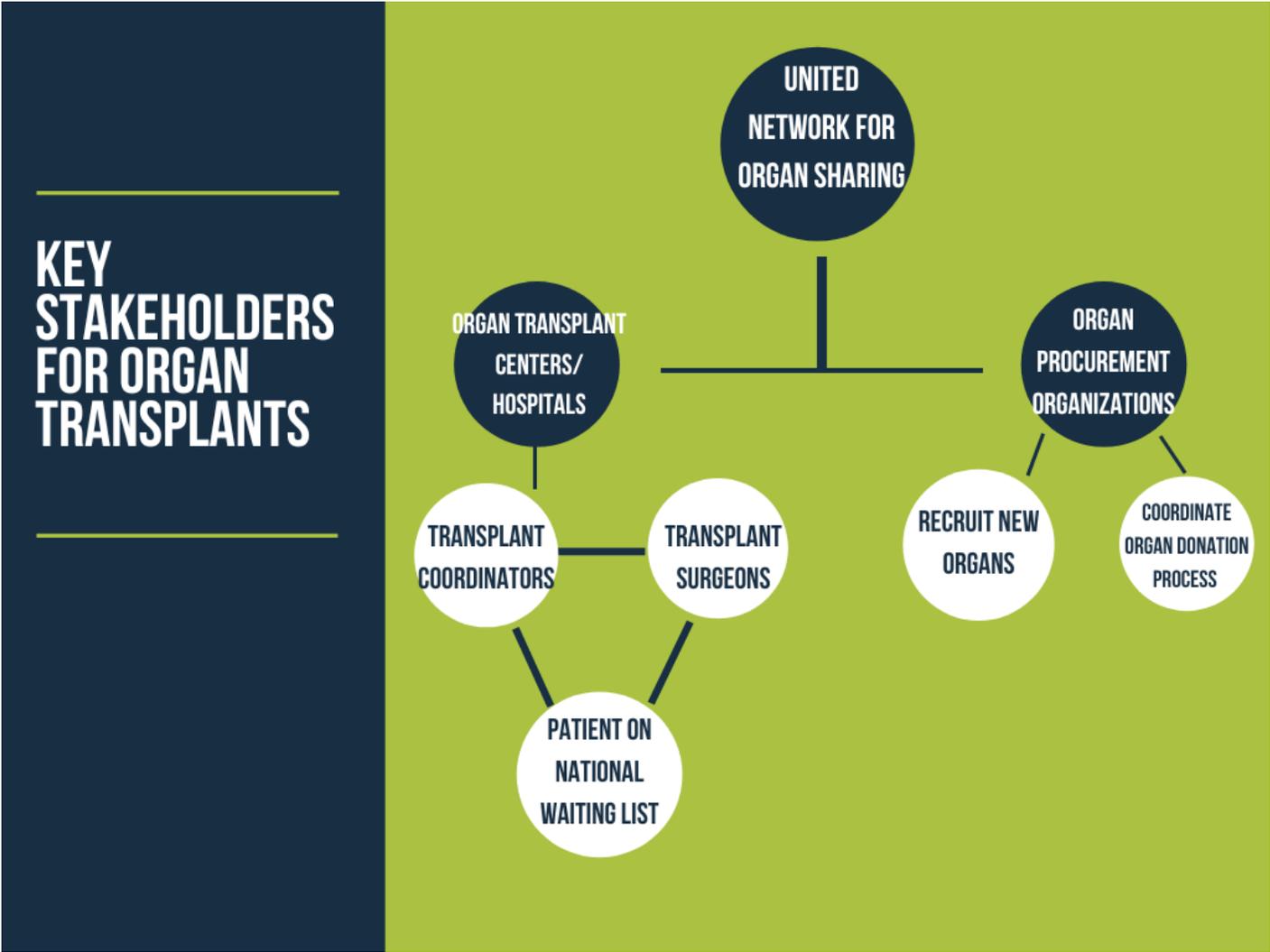
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Figure 1: Key Stakeholders for Organ Transplants

The below picture explains who is involved in organ transplants.



Glossary



Accommodations: Changes that help people with disabilities get the same services as others.



Agency: A part of the United States government.

Allocation: Deciding who gets something.



Americans with Disabilities Act (ADA): A law that was passed in 1990. It is about the rights of people with disabilities.



App: A program on a computer.



Barriers: Things in the world that stop doctors from giving people with disabilities what they need.



Bias: Another word for prejudice.

Blood pressure: Has to do with how your blood moves through your heart. If it is higher than normal, this is bad for your heart.

Caregiver: Person who helps another person with daily living.



Center for Dignity in Healthcare for People with Disabilities: A coalition. We work on making health care better for people with disabilities. www.centerfordignity.org



Circle of support: A whole group of people who help another person make choices.



Coalition: A group of people who know a lot about something.



Community: A place where people live.



Criteria: A list or paper that says how a decision is made.

Data: A kind of evidence. Data is evidence that is put together. It is mostly numbers. Sometimes it is facts.



Diagnosis: Another word that means your disability or health problem.



Discrimination: Treating someone or a group of people differently because of who they are.



Donor: The person who gives another person their organ.

Ethical: Whether something is the right or wrong way to do something. This does not mean true or false. It means whether it is fair or not fair.



Ethicists: People who think about what is right and wrong for a living. This is not what is true or false. It is about what is fair or not fair.



Evidence: A fact that shows something is true.

Explicit discrimination: When the person who is discriminating knows that is what they are doing.



Gap: A place in laws or rules where discrimination is not stopped. There are also gaps in what people know.

Gap analysis: a research paper where people try to find out how to fix a problem.

Graft - When doctors do surgery when only a part of an organ stops working. They take out the part that is not working. They put in a working part instead.



Guardian: Someone who makes choices for someone else. A court makes them a guardian.

Guardianship: Where someone else makes choices for a person with a disability.



Guidelines: Rules that people follow.



Health care inequity: When a group does not get the same health care as everyone else. This is not fair.



Home and Community Based Services (HCBS): LTSS services in the community.



Implicit bias: When the person who is discriminating does not know they are discriminating.

Individually: When doctors just look at the person by themselves.

Long Term Services and Supports (LTSS): Services that help people with disabilities live their everyday lives.

Medical Schools: Where doctors are trained. Doctors are also trained in hospitals.



Modifications: Changing the rules you follow so a person with a disability can use your service.



National Council on Disability: An agency. They tell other agencies how to make people with disabilities' lives better.
www.ncd.gov

Opaque: When people can't see or understand something.



Organ: A really important body part. A heart is an organ.



Organ Allocation: Deciding who gets an organ.

OPTN

Organ Procurement and Transplantation Network (OPTN): The group organ transplant centers talk to when they want to do a transplant for someone.



Organ Transplant Center: Where a person has the surgery to get an organ. Organ Transplant Centers decide who gets an organ transplant.



Oversight: A word that means that there are people who make sure that something is done right.



People with intellectual and developmental disabilities (I/DD): A kind of person with a disability. We will call them I/DD for short. People with I/DD mostly have a disability as soon as they are born. They do things differently than other people. They think differently too.



Person-centered care: When the doctor looks mostly at what the person wants from health care. This makes the person's health better.



Person-centered plan: A paper that says what a person wants to happen, what the best way is to do it, and who will do it.



Person-centered planning: Where a doctor and a person make choices about the person's health care together. It can be a big part of person-centered care.



Post-operative care: Things you have to do after a transplant to keep your new body part working.

Prejudice: When you believe something bad about another person because of who they are.



Quality of Life – How good your life is. Part of your quality of life has to do with your health care.



Recommendations: Papers that tell people how they should do something.

Research: A way that we show that something is true. Research makes research papers and studies.



Research paper: A paper where people study something and then write down what they think is true.



Selection: Choosing between more than one thing.



Self-advocacy: When a person is able to tell other people what they need.

Society: A very big community made up of smaller communities. An example is the United States.



Stereotypes: A kind of idea about a group of people. The idea is that everyone in the group is the same. They can hurt people.

Strengths-based approach: Where doctors look more at what the person can do than at what they can't do.



Study/Studies: Another word for research papers.



Supported decision-making: Making choices with help.

Support person/people: A person or several people that help other people make choices.



Surgery: A doctor opens up your body. The doctor does something to the inside of you. You need surgery for transplants.



Transparency/Transparent: A word that means that everyone can see and understand something.



Transplant: When a doctor takes a body part from one person and puts it in a different person.



United Network for Organ Sharing: They run the OPTN. They make transplant rules for the entire United States.



Waiting List: A list your name has to be on in order to get an organ. People on the list wait for their turn to get a transplant.