



Aging/End of Life Recommendations- 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 better healthcare at the end of their life or as they age.

Part I will answer these questions:

- What is aging?
- What does End-of-Life mean?
- Why is it important that we improve healthcare for people with disabilities as they age or at the end of their life?
- 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 care as they age or at the end of their life?
- How did the Center for Dignity study Aging/End of Life?
- How did we fix gaps?
- Why do people with disabilities not receive good healthcare as they age or at the end of their life?



- How does the Americans with Disabilities act get rid of discrimination in Aging or End of Life Care?

What Is Aging?

Aging is the process of getting older.

People with disabilities have not always had the resources and supports to get to be as old as they are today.

Resources are things like better healthcare and improved research.

Research is a way that we show that something is true.

Supports are tools that can help a person with a disability live a longer life.

What does End-of-Life mean?

End-of- Life is when a person is in their final weeks or months of their life.

End-of-life care is helping someone to live the best they can before they die.

This care can be helping them not be in pain or asking where they want to be when they die.

People with disabilities are not always asked their final wishes and preferences.

The Center or Dignity wants to change that.

We want people with disabilities to be part of how they age or the type of care they receive at the end of their life.

Health care professionals now have to think about new things as people with disabilities are aging.

Health care professionals are people that give medical treatment and advice.

They have received lots of education to do this.

Examples of healthcare professionals are doctors, nurses, physical therapists, and social workers.

Why is it important that we improve healthcare for people with disabilities as they age or at the end of their life?

People with intellectual and developmental disabilities (I/DD) are now able to become older than ever before.

People with Intellectual and Developmental Disabilities have a specific type of disability.

We will call them **people with I/DD** for short.

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 in how people with IDD age and the care they receive at the end of their life.

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.

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 the 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)**.

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 Aging and End-of-Life care.

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 helping people with I/DD get better care as they age and at the end of their life.

How did the Center for Dignity study Aging/End of Life?

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 aging, end-of-life care and people with disabilities.

People with disabilities were not receiving good communication about aging or the end-of-their life.

Decisions about their healthcare were being made without them.

Due to a lack of research, it is also often hard to know when a person with I/DD is about to die.

Sometimes people with I/DD are told they are going to die when they really are not going to die.

Sometimes people with I/DD are told they are not going to die when they really are going to die.

The Center for Dignity studied these problems to try to fix them.

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

The Center for Dignity wants everyone to receive Aging and End-of-life healthcare that needs it.

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** is a place where discrimination is not stopped.

A gap can be in:

- The laws
- The rules
- The things people know

You have to make a plan to get rid of the gaps. Our gap analysis did this.

How Did We Fix the 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 for aging and end-of-life care.

Our recommendations tell people how to do all these things.

Following our recommendations will help people with disabilities receive better healthcare as they age and at the end of their life.

Why do people with disabilities not receive good healthcare as they age or at the end of their life?

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 with disabilities to get care as they age or at the end of their life.

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 good healthcare 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. 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.

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 Aging or End of Life Care?

One way to fix it is by giving everyone **accommodations**.



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

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**.

Modifications are a way of changing the rules.

The rule would say something different.

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.

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

Part II- Training

In Part II, we will answer these questions:

- Who are Healthcare Professionals?
- What is training?
- What are standards of care?
- What are healthcare inequities?
- What is palliative care?



Healthcare professionals are people that give medical treatment and advice.

We believe that healthcare professionals need to be taught how to treat and support people with disabilities.

Many of these people have never learned how to work with people with disabilities.

They could be better at helping people with disabilities if they got better training about disability.

Training is another word for education.

People that work in healthcare should have high standards of care for people with disabilities.

Standards of care are the rules for giving medical treatment or advice to a specific type of disability.

We want there to be high standards when treating people with disabilities.

When there are not high standards of care, we see **healthcare inequities** for people with disabilities.

Healthcare inequities are when a group does not get the same health care as everyone else.

Sometimes this means that people with disabilities do not get offered the same treatments as nondisabled people.

Sometimes this means that people with disabilities die for reasons that could have been fixed.

For people with disabilities, this is often due to ableism.

This is why it is important for healthcare professionals to learn about people with disabilities.

Learning about disability will lessen ableism within healthcare.



They could learn about people with disabilities through:

- Volunteering
- Classes
- Research
- Reading

We want healthcare professionals to get to know people with disabilities by talking to them.

This will help healthcare professionals learn how to help people with disabilities who are aging or at the end of their life.

In a recent **study**, 40% of doctors said they were 'very confident' about how they took care of patients with disabilities.

This means that only two out of five doctors felt positive about treating patients with disabilities.

Better training about disability can help doctors feel more confident in treating patients with disabilities.

Palliative Care doctors said they do not have any experience and are not confident in caring for patients with I/DD during end-of life.

Palliative Care is special medical care that helps people with long-term healthcare problems. They also give end-of-life care.

We want more doctors to feel positive about treating patients with disabilities.

We believe that all healthcare professionals should have more training. This training should include person-centered care.

The next section will explain person-centered care.

Part III- Person-Centered Approach to Decision Making

In Part III, we will answer these questions:



- What are End-of-life decisions?
- What if the patient with a disability is not able to communicate their end-of-life decisions?
- What is End-of-life planning?
- What is person-centered care?
- What is person-centered planning?
- How does guardianship impact how decisions are made?

Research shows us that people with disabilities are sometimes not included in their own end-of-life decisions.

End-of-life decisions are the choices someone wants to make before they die.

One **study** showed that adults with I/DD were not very involved in their care.

Some did not even know they were dying.

This happens more with people with disabilities than people that do not have a disability.

Sometimes this is because it is hard to talk about death and dying in our society.

The **gap analysis** showed us that people find it even harder to talk about death and dying to people with I/DD.

We want this to change.

We believe that people with I/DD should be included in their own end-of-life decisions.

What if the patient with a disability is not able to communicate their end-of-life decisions?

Some adults with disabilities are not able to tell someone their end-of-life decisions.

Sometimes this is because the person does not speak.

If a person cannot communicate their end-of-life decisions, an accommodation should be provided.

An **accommodation** is to provide an alternative way of doing something to help people with disabilities get the same services as others.

An example of an accommodation to help someone communicate might be a picture board.

Picture boards helps someone to tell others what they are thinking without speaking words.

It is very important to provide an accommodation so that a person can say how they want end-of-life care.

It is also important for them to say what their quality of life should be.

Quality of life means how good a person's life is.

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.

What is End-of-Life Planning?

We want end-of-life planning to be person-centered.

End-of-life planning is how a person wants medical care before they die.

We want the patient with the disability to be included in this planning.

People with disabilities are not always included in this plan.

We want this to change.

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.

How does Guardianship Impact How Decisions are Made?

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

We think it should happen when a person with a disability is aging or is at the end of their life.

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.

See Appendix A for more on this topic.

We want better rules and laws on guardianship.

We want these laws to say that people with I/DD should be part of all decision-making processes.

Part III- Improve Diagnosis and Treatment at End of Life

In Part III, we will answer these questions:



- What is Diagnostic Overshadowing?
- What is Stigma?
- What is Discrimination?
- How do Stigma and Discrimination Impact Healthcare?

Healthcare Professionals sometimes think a person's disability is the cause for all of their symptoms.

This is called **Diagnostic Overshadowing**.



People with I/DD often experience diagnostic overshadowing.

Diagnostic, or diagnosis, is another word for disability or health problem.

Overshadowing means that it is seen as more important.

Diagnostic overshadowing is when a person's disability is seen as more important than any other problems they might be having.

How do Stigma and Discrimination Impact Healthcare?

People with I/DD experience a lot of stigma and discrimination within the healthcare system.

Stigma is a negative belief about someone that has a disability.

Some Healthcare Professionals have a stigma that people with disabilities are helpless or have a poor quality of life.

Discrimination is what someone does when they have stigma about a person.

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

Healthcare professionals sometimes discriminate against people with disabilities by denying them care, such as pain medicine at the end of their life.

This stigma and discrimination causes people with I/DD to receive poor quality of healthcare.

Healthcare professionals often make mistakes when they believe a person with I/DD's symptoms are related to their disability.

This happens a lot at the end of life for a person with I/DD.

Part IV - Address Gaps in Information and Improve Research

Research is needed about the health of people with I/DD as they get older.

Research is a way to show that something is true.

We need to show that people with I/DD have different health needs than those without I/DD as they get older.

We want research that uses prospective, longitudinal methods.

Prospective, longitudinal research methods are when you try to find out what is true about someone's life over a long period of time.

We also want this research to show how the brain of a person with I/DD changes as they get older.

Further, we also need to study whether people with I/DD are able to make their own decisions as they get older.

We really want to know if people with I/DD can make their own decisions about **end-of-life care**.

We do not have research yet about whether people with I/DD are asked about their end-of-life care.

We mostly do not know if people with I/DD get to make their end-of-life decisions or not.

Summary and Additional Recommendations

We want healthcare professionals to have a rule in place when they treat patients with disabilities.

This rule would make sure that people with disabilities are able to participate in making decisions about their healthcare.

Participating in making decisions about their healthcare would be different for each patient.

Some patients would be able to participate more than others.

Some patients might need an accommodation to participate.

Some patients might have a direct support professional.

Direct Support Professionals are those who work with people with disabilities to become more integrated into their community.

More integrated into the community means that a person can participate in any part of society.

It is important that doctors know that the patient with a disability may not know the direct support professional.

The doctor may need to help find someone else that can help a person with I/DD to make decisions about their end-of-life care.

Healthcare professionals should also know more about the problems that come up with guardianship and aging for people with I/DD.

You can find more information about this in **Appendix A**.

Conclusion

We recommend training for healthcare professionals.

This training should be about caring for people with I/DD who are aging and/or facing end-of-life decisions.

Healthcare professional groups should include more information at their conferences, trainings, and on their websites.

One example of a healthcare professional group is American Academy of Hospice and Palliative Medicine.

This group wants to have more information on these topics.

Many healthcare professionals also want more information and training.

Appendix A

Guardianship and Decision Making

There are a lot of challenges that come up in aging and end of life care for a person with IDD that has a guardian.

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

The person who makes the choices is called a guardian.

We have provided two case studies to answer these challenges.

Case studies are another word for an example of a real-life situation that this happened.

Case Study #1: Guardianship and Sarah McSweeney

Background: On April 21, 2020, Sarah McSweeney, a patient with a disability, went to the emergency room with a high fever.

Her real name was not Sarah McSweeney.

We are calling her that to keep her information private.

Tests showed she did not have COVID-19.

She had times that fluid backed up into her lungs while she was being fed.

This is called **aspiration pneumonia**.

Sarah lived in a group home.

She had multiple disabilities.

She was quadriplegic. She could not swallow. She could not speak.

The people that worked with her could understand her by her sounds and facial expressions.

Case presented:

Sarah was not able to communicate her wishes.

This caused a problem for the healthcare professionals.

How would they know what Sarah McSweeney wanted?

Her doctor's and nurses questioned if she had a good quality of life in her group home.

Quality of life is how much someone enjoys living their life.

The doctors thought about intubating her to let her lung rest.

Intubating is when a tube is inserted through a person's mouth or nose and down their airway.

This tube is connected to a machine that gives your body oxygen.

Intubating her would give Sarah time to heal and let the medicine work.

Outcome:

Sarah McSweeney was not put into the ICU.

She was not intubated.

Sarah McSweeney died on May 10th as a result of **aspiration pneumonia**.

Considerations:

Sarah McSweeney lived in the group home for almost 15 years.

She had caregivers that knew her well from the group home.

These caregivers knew how to communicate with her.

They knew what she wished her life to be like.

The medical team only worked with the caregivers sometimes.

When they decided if Sarah should be intubated, they did not listen to what she would have wanted.

They also did not listen to Sarah's Guardian.

Sarah McSweeney died too early. She could have lived longer. She did not have to suffer.

Conclusion:

This case study shows the lack of understanding about guardianship in the healthcare system.

This case study is a good example of how disability discrimination happens within health care.

Recommendations:

Sarah McSweeney is a good example of the difference in how a patient and doctor understand the quality of one's life.

Patients with disabilities often measure a life worth living very differently than patients without disabilities.

Doctors often believe that having a disability means you have a lower **quality of life**.

This is one type of disability bias.

Bias is another word for prejudice.

This bias about disability can put a doctor and patient with a disability in an adversarial role.

Having **adversarial roles** means that there are two sides that are against each other.

If they are against each other, the doctor and patient can not have a person-centered approach to their healthcare.

Case Study #2: Baby Doe

In 1982 a baby was born with Down Syndrome.

The baby also had a heart condition that required surgery.

The parents of the baby refused the surgery.

They said they did not want the baby to have heart surgery because it had Down Syndrome.

The hospital did not think this was a good reason not to have the surgery.

They selected a guardian for the baby.

A judge later ruled that the baby should not have a guardian.

The judge decided that the parents could decide if the baby should have this surgery or not.

The baby died as a result of not having the heart surgery.

This story is called the Baby Doe case.

Medical/Bioethical Protocols for Surrogate Decision Making

There are several cases, including Baby Doe, that established laws for hospitals.

These laws state that hospitals must provide life saving treatment to disabled babies.

These must be provided whether the parent wants them or not.

If the hospital does not provide life saving treatment they will risk losing federal funding.

Life saving treatment is when someone gets medical care that they would need to stay alive.

Federal funding is money from the government.

The only time a hospital does not have to provide life saving treatment is if the baby:

- is in a permanent coma
- terminally ill
- or if the treatment itself is “inhumane.”

A **permanent coma** means the baby is asleep and will never wake up.

Terminally ill means the baby is so sick that it will die no matter what doctors do to try to help.

A **treatment is inhumane** if it causes a lot of pain and would not help the person get better.

Substituted Judgment Standard

A **surrogate** is a person that helps make decisions when someone is unable to.

These decisions are about a person's health care.

The **Substituted Judgment Standard** is used when a person once had the ability to make decisions, but has now lost that ability.

Since they once had the ability to make decisions, the surrogate will know what they would want if they could say themselves.

Example:

Kendrick was an average 35 year old male.

He had a job, a spouse, and he loved the color purple. He attended Catholic church every Sunday.

Kendrick was in a car accident that caused him to have a brain injury.

In the hospital, Kendrick was on a lot of medications that made him sleepy.

He could not talk.

His spouse, Suparna, became his surrogate decision maker.

She was able to make decisions for Kendrick because she knew him before the accident.

She knew what Kendrick valued in life.

She can easily guess what he would want if he were able to tell her.

Best Interest Standard

Sometimes we do not know anything about a person when a surrogate needs to help make decisions about their healthcare.

The **Best Interest Standard** is used when a person has never been able to say what they want.

It can also be used when we do not have any information about what they would want.

This standard will ask the surrogate to choose what is in the patient's best interest.

This means making choices that will help their quality of life.

The surrogate is not able to guess what the patient themselves would want.

These choices are based on how a '**reasonable person**' would decide what most people would want.

A 'reasonable person' is how we describe how most people think about healthcare and quality of life.

A reasonable person is supposed to make decisions that most others would agree with.

The Baby Doe Case uses this standard.

Recommendations:

A surrogate should not include their own values or views when making a decision.

This will allow the surrogate decision maker to avoid **bias**.

This surrogate decision maker should:

- Trust information about the patient's previous wishes
- Make decisions that an objective third party would agree with.

An **objective third party** is someone that is not related to or friends with the patient.

This person will not benefit or be harmed in the decisions that are made for the patient.

Why These Protocols Do Not Account for the Particularity of Guardianship

The **Substituted Judgment Standard** and **Best Interest Standard** should not be used when the person has a **guardian**.

These standards only consider:

- information about the patient's previous wishes
or

- judgements that would be endorsed by an objective third party

These standards do not consider a person's current wishes if it has been decided by a judge that the person does not have the ability to make decisions.

Such as people who have guardianships.

When someone has a guardian, they sometimes have opinions about what healthcare they need, but can not make the decision by themselves.

Policies need to be made for people in this situation.

But many people with guardians still have **preferences, values or beliefs** about their own healthcare.

A preference is a person's first choice.

A value is how important something is to someone.

A belief is something regarded as true by someone.

A new standard is needed that will include the person's preferences, values or beliefs into the healthcare decision process for people with guardians.

There are lots of problems with the guardian relationship.

No one agrees about what to do when someone disagrees with their guardian about a medical decision.

There should be a way for a person with a disability to have a say in what happens with their medical care.

This should especially be true when their guardian disagrees with them.

The problem is that people with disabilities usually cannot change their guardians.

They also can't ask the court to remove their guardianship.

This is not something that doctors deal with directly.

However, it causes problems for people with disabilities when they need to see a doctor.

We need to figure out how to fix these problems.

Recommendations

The **Substituted Judgment Standard** and **Best Interest Standard** may work well to make sure that people with disabilities do not experience medical neglect.

They may also work well to make sure people with disabilities do not experience abuse from caregivers.

In cases of guardianship, another standard should be used to make sure the patient's wishes are part of the decision making process.

This standard should be used even if the patient has been determined to be '**incompetent.**'

Incompetent is someone that is not able to make decisions.

These decisions often look like they are objective by a reasonable person, such as a doctor or judge.

However, they are usually biased by an ableist culture.

An **ableist culture** is a society that is built on the idea that it should be acceptable to think disability is a bad thing.

It is very important that the individual patient is able to make their own judgment on their quality of life.

Another person should not be able to decide what a person with a disability's quality of life is.

We do not think another person should decide this because they usually assume that disability worsens a person's quality of life.

Glossary:

Ableist Culture is a society that is built on the idea that it should be acceptable to think disability is a bad thing.

Adversarial roles: Two sides that are against each other.

Ageing is the process of getting older.

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

Belief: something regarded as true by someone.

Best Interest Standard: used when a person has never been able to say what they want. It can also be used when we do not have any information about what they would want. This standard will ask the surrogate to choose what is in the patient's best interest.

Bias: Another word for prejudice.

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

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

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

End-of- Life: when a person is in their final weeks or months of their life.

End-of-life care: helping someone to live the best they can before they die. This care can be helping them not be in pain or asking where they want to be when they die.

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

Evidence: are facts that show something is true.

Gap: a place in laws or rules where discrimination is not stopped.

Gap Analysis: a kind of **research paper**.

Guidelines: rules that people follow.

Healthcare inequity: something is not equal. It means something is not fair. Health care for people with disabilities is not equal and not fair right now.

Health care professionals: people that give medical treatment and advice.

Incompetent: not able to make decisions.

Objective Third Party: someone that is not related to or friends with the patient. This person will not benefit or be harmed in the decisions that are made for the patient.

People with intellectual and developmental disabilities (or People with I/DD): have a specific type of disability. People with I/DD have a disability as soon as they are born. That disability makes them think differently than other people.

Preference: a person's first choice.

Prospective, longitudinal research methods are when you try to find out what is true about someone's life over a long period of time.

Reasonable Person: is how we describe how most people think about healthcare and quality of life. A reasonable person is supposed to make decisions that most others would agree with.

Research is a way that we show that something is true.

Research Paper: is a paper where a group of people try to find out if something is true. The people find out what they think is true by studying it. The people write down what they found out.

Resources: things like better healthcare and improved research.

Substituted Judgment Standard: used when a person once had the ability to make decisions, but has now lost that ability.

Supports: tools that can help a person with a disability live a longer life.

Surrogate: a person that helps make decisions when someone is unable to. These decisions are about a person's health care.

Value: how important something is to someone.