



The rights of people with disabilities.



What the Special Rapporteur did in 2019

The human rights of people with disabilities in science and medicine



EasyRead version of:

Report on the impact of ableism in medical and scientific practice of the Special Rapporteur on the rights of persons with disabilities (A/HRC/43/41).



1. About this report **1**



2. What the Special Rapporteur did **3**



3. Not valuing people's lives **5**



4. Science, medicine and people with disabilities **8**



5. What the law says about rights and people with disabilities **13**



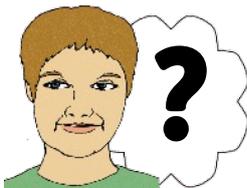
6. Things that stop people with disabilities having these rights **15**



7. How to help people with disabilities get these rights **21**



8. What happens next? **32**



9. What the words mean **36**



Hard words are in **bold**.
These words are explained
in a list at the end of this report.

1. About this report



SUN	MON	TUE	WED	THU	FRI	SAT
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
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29	30	31				



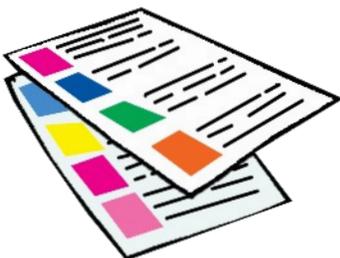
Every year the **Special Rapporteur** on the rights of persons with disabilities writes reports to tell the **United Nations** about **human rights** and people with disabilities.



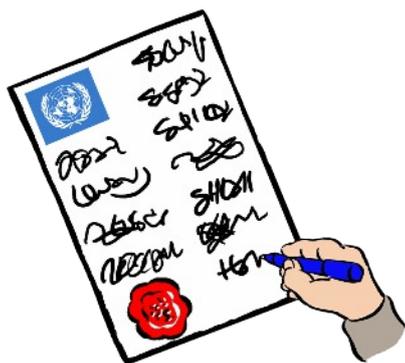
The Special Rapporteur is Catalina Devandas Aguilar. She helps countries understand how to make sure people with disabilities can get their human rights.



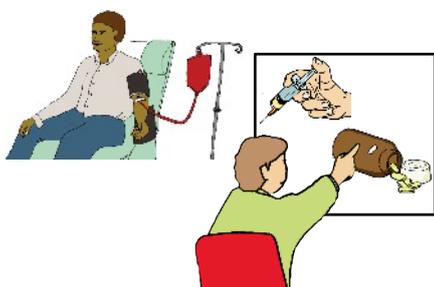
The United Nations is a group made up of 193 countries. They work together to make the world a safer and better place for everyone.



This is an EasyRead version of the Special Rapporteur's report about how science and medicine can affect the rights of people with disabilities.



An international agreement called the United Nations **Disability Convention** says people with disabilities have the same human rights as everyone else.



This includes the right to medical treatment and to be involved in decisions about treatment and dying.



With her report the Special Rapporteur wants to make sure all countries follow the United Nations Disability Convention. This means thinking about human rights in laws and rules about research, treatment and **assisted dying**.

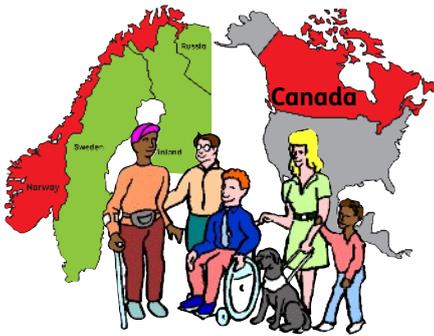


Before she wrote her report the Special Rapporteur spoke to governments, experts, organisations and people with disabilities and their organisations.



2. What the Special Rapporteur did

In 2019 the Special Rapporteur:



- visited Canada and Norway to find out what life is like for people with disabilities in these countries



- talked about rights and people with disabilities at conferences and meetings in different countries



- wrote reports about taking away the freedom of people with disabilities and about the rights of older people with disabilities. There are EasyRead versions of these 2 reports



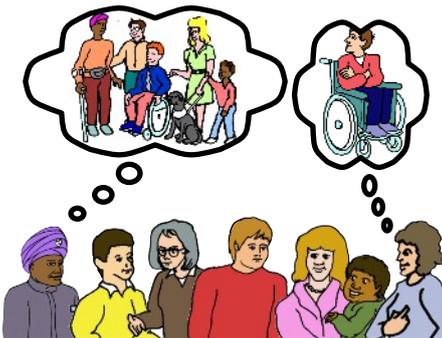
- helped the United Nations to adopt a plan to make it more accessible, to include people with disabilities and have people with disabilities working in the organisation.



3. Not valuing people's lives



Most countries understand that people with disabilities have the same rights as everyone else. But there is still **discrimination** against people with disabilities.



This happens when other people think another person's life has less value because they have a disability. Many people wrongly assume that their lives are sad and they have no future.

This type of discrimination is called **ableism**.



But people with disabilities can live a good and happy life.



In the past many people with disabilities were **sterilised**, used in **research** or killed. This happened because other people thought they were not worth living.



Today people with disabilities are still treated worse than other people by laws that:

- keep them away from other people



- take away their right to freedom



- take away their right to make decisions.



When people have bad experiences it is not usually due to their disability but because:

- there is discrimination or **prejudice**



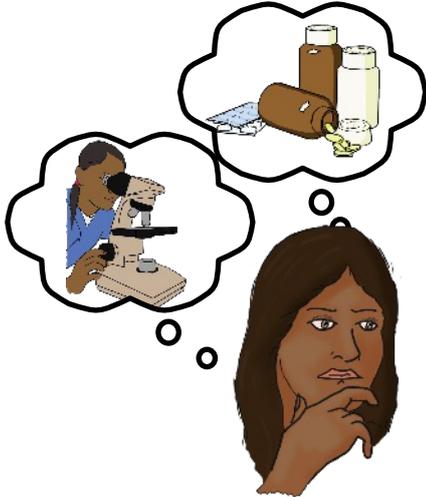
- other people have wrong ideas about what they can do



- services do not make the changes they need.



4. Science, medicine and people with disabilities



Bioethics means thinking about how new ideas in medicine, science and research could and should be used. It should be based on human rights and valuing people's lives.

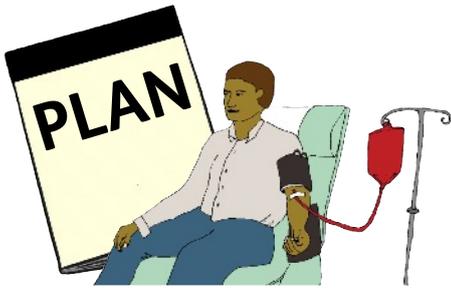


Bioethics helps governments to think how laws in research and medicine should look like.



These laws help scientists, doctors, families and patients make plans and decisions about:

- research



- treatment



- care

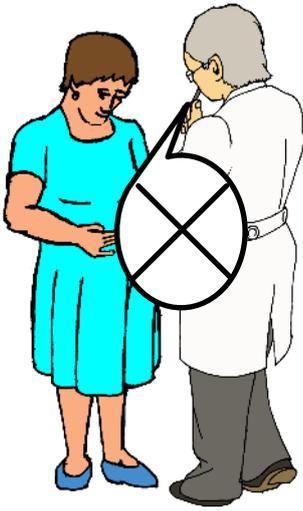


- dying and assisted dying.



Developments in science means doctors can now:

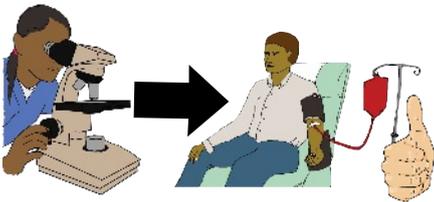
- test mothers to see if their baby will have a disability



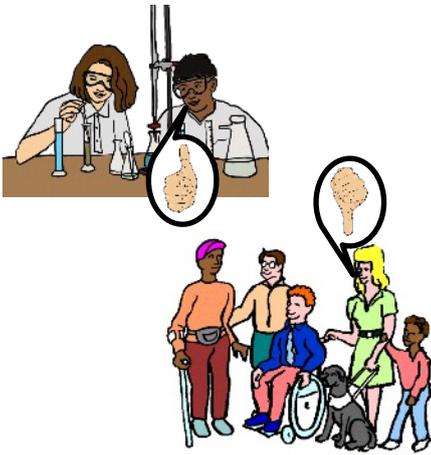
- abort babies that will be born with disabilities



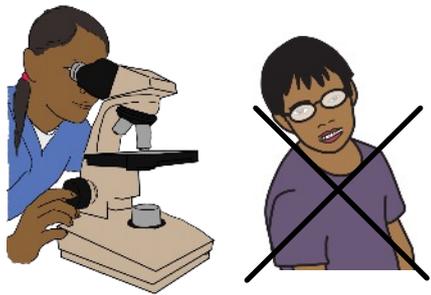
- treat parents to try to stop them having a baby with a disability.



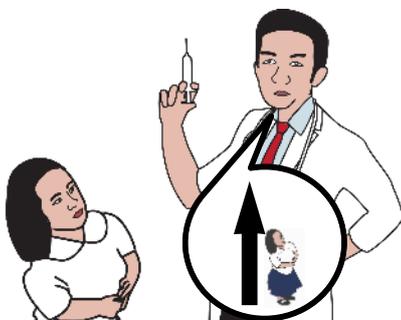
Everyone wants science and research to lead to better choices about medical care.



But scientists and people with disabilities often see things differently. So decisions about science and medicine might not be based on what is important to people with disabilities:



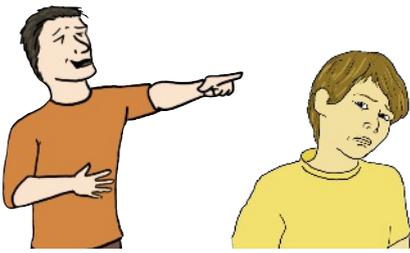
- scientists might look for ways to stop people becoming disabled or to cure disabilities



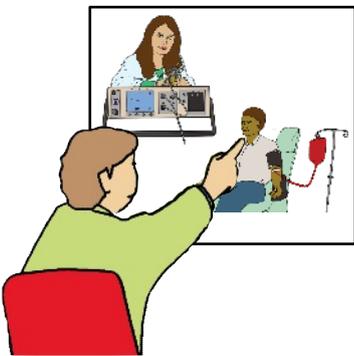
- some people might want to find a cure or treatment for their disability



- other people with disabilities think it is an important part of who they are. They do not want to change themselves. But they do want the same rights and chances in life as other people.



- some people with disabilities think that trying to stop or cure disabilities could make people's bad attitudes about people with disabilities even worse.



All people with disabilities should have the chance to make decisions about medicine and science that affect their lives.



Bioethics should recognise the rights and concerns of persons with disabilities, paying close attention to their own voices, needs and choices.



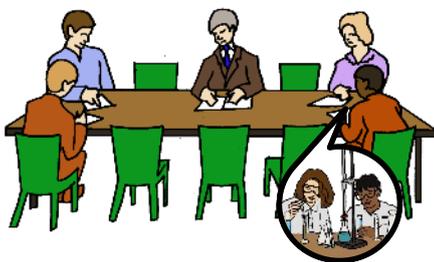
5. What the law says about rights and people with disabilities



The Disability Convention says human rights are for everyone. This means everyone's life is important and valuable. Whether or not they have a disability.



But governments do not usually involve people with disabilities when they make laws about medicine and science.



They listen to committees of people who are experts in science and medicine. But do not know what it is like to have a disability.



Bioethics should protect the human rights set out in the Disability Convention.



But this can only happen if governments involve and listen to people with disabilities when they make new rules and laws about science and medicine.



6. Things that stop people with disabilities getting these rights



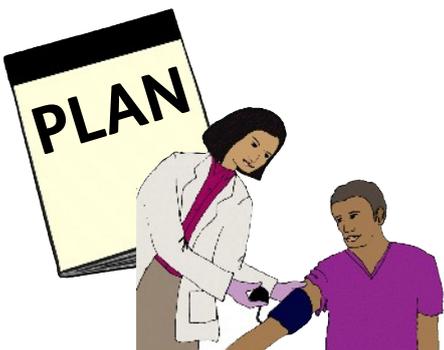
The Special Rapporteur found that science and medicine discriminate against people with disabilities for many different reasons.

Here are some examples.

Reason 1: **Stigma** and **stereotypes**



Most governments spend more time planning how to stop people being disabled. And less time making sure society includes and is **accessible** to people with disabilities.



Plans to keep people healthy are important.



But they might not protect the rights of people with disabilities or give them better lives.

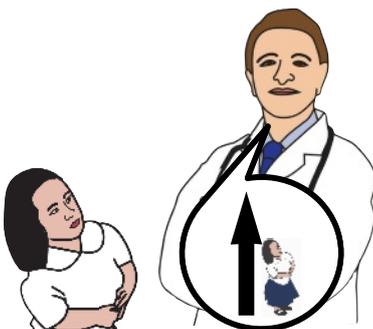


Sometimes these plans make other people more prejudiced against people with disabilities.

Reason 2: Discrimination



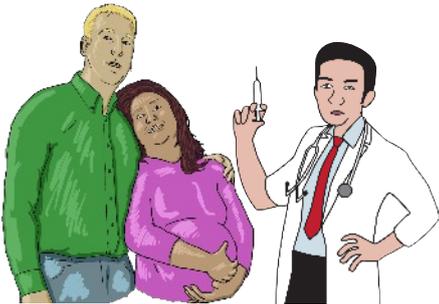
It can lead to discrimination when other people think a person's life is not worth living if they have a disability. This means families and doctors:



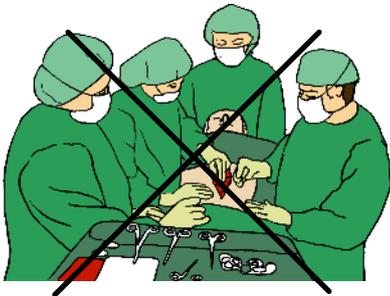
- feel they must cure a child's disability or try to make them look like other people



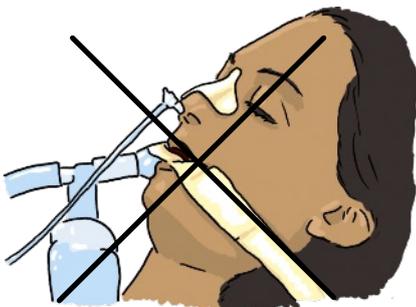
- give people medicines that change their behaviour so they do not act as who they are



- test or treat women to stop them having a baby with disabilities

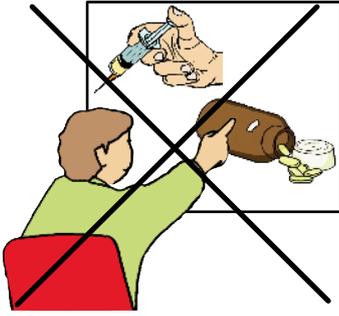


- do not think it is worth giving people with disabilities **organ transplants**



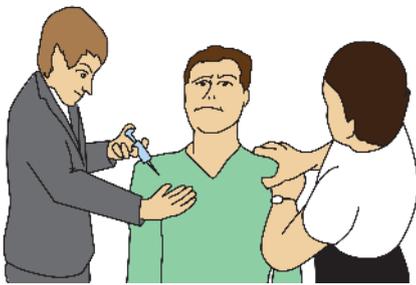
- do not give people with disabilities the treatment they need if they are seriously ill.

Reason 3: Thinking people with disabilities cannot make decisions

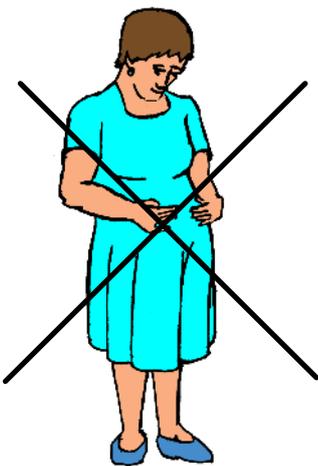


Other people and services often think people with disabilities cannot make decisions for themselves.

This can mean:



- people with mental health problems, learning disabilities, **dementia**, or **autism** are given treatment or are involved in research they do not agree to



- some women with disabilities are sterilised, given abortions or not allowed to have babies



- people with disabilities are not involved when governments make rules and laws about medicines and treatments.

Reason 4: Not having enough support



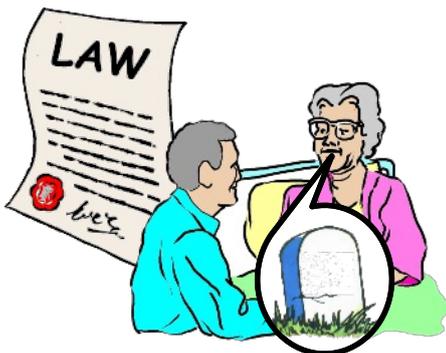
People with disabilities should have the medical treatment they need and enough money or support to live an **independent** life.



If they do not have this, they might feel they are a problem to other people and they have nothing to live for.



Assisted dying is when a person asks someone else to help them end their life. This usually happens when the person has a serious illness and wants to choose when and how they die.

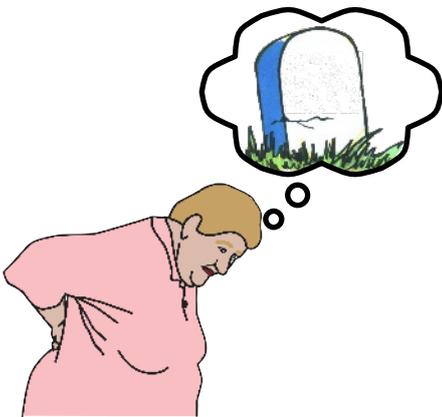


At the moment only 8 countries have laws that allow this to happen. But other governments are thinking about it.



People with disabilities worry that if assisted dying is legal for anyone then:

- someone who has just become disabled might think it is better to die than to try to cope with the disability



- people with disabilities who are lonely, in pain or do not have any **support** might choose to end their lives



- people with disabilities might feel their families want them to end their lives because they need so much care.



7. How to help people with disabilities get these rights



The Disability Convention can help to make sure laws about science and medicine respect the human rights of people with disabilities.



The Convention says it is not their disability that stops people doing things they want to do. This happens when they cannot access school, college, work, buildings, services, support or transport.



Governments, services and communities must get rid of things that stop people with disabilities having the same chances as other people.



The Special Rapporteur says these are some of the ways governments can give people with disabilities better rights.

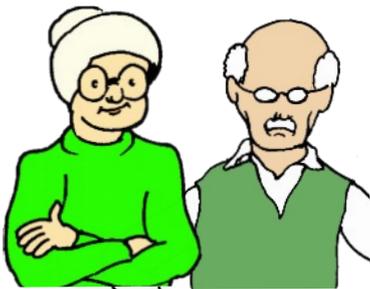
Use the Disability Convention



The word **dignity** is used many times in the Convention. It means every person is important because they are humans, so they deserve to be treated with respect. This includes people with disabilities.



The Disability Convention says governments must make sure other people understand that people with disabilities have the same human rights as everyone else.



These include the right to:

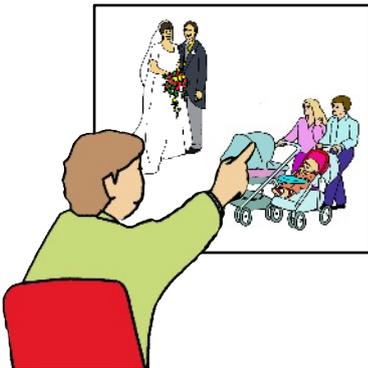
- live long and healthy lives



- have support and information to be involved in decisions. Even if other people do not agree with these decisions



- have privacy and not have other people share information about them without their permission



- make choices about things like relationships, being a parent or getting married



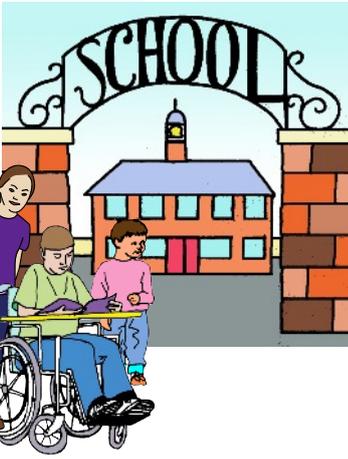
- have good healthcare and choices about treatment or medicine



- have support to live independently

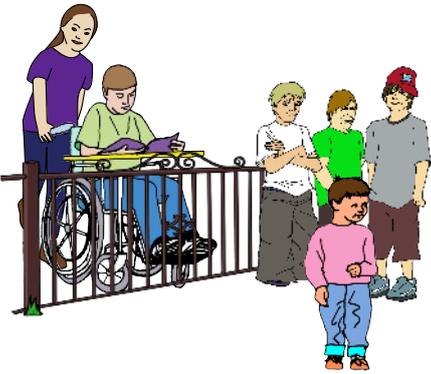


- be respected for who they are and not have treatment to change or cure them unless they choose this.



Stop discrimination

When people with disabilities go to school with other children or adults are involved in their community it can help other people understand, respect and value their contribution.



But discrimination happens when people with disabilities are kept apart or treated differently. Then other people think a person's life is less important because they have a disability.



Governments must get rid of laws that treat people with disabilities less fairly than other people.



This means stopping all types of discrimination such as:

- not having choices or support to make choices



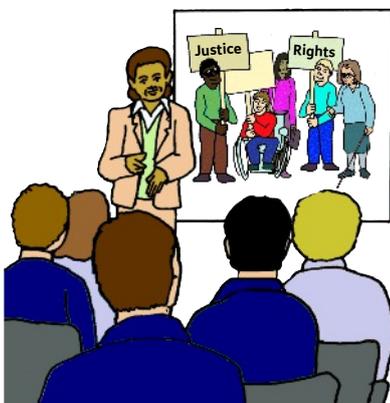
- not having support or services to live independently



- not having the same rights and chances as other people.



In medicine and science this can mean people with disabilities are given treatment they do not want. Or might not get the medicines or treatment they need.



People who work in health and care services must have training about human rights and people with disabilities.



Think about human rights in tests for disability

Governments can have plans to stop people becoming disabled and still follow the Disability Convention. But they must think about human rights.



This means governments should:

- not say anything that makes other people think life is not worth living if you have a disability



- still spend time and money to make sure people with disabilities have the same rights and chances in life as other people.



Pregnant women need clear and balanced information before they have tests to see if their baby could have a disability. This includes:

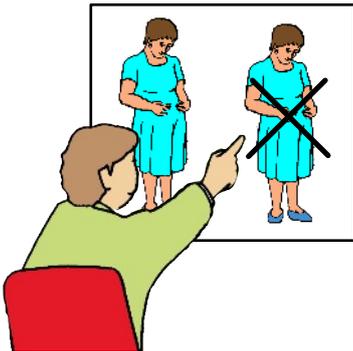
- what the test can tell them and whether it could harm the baby



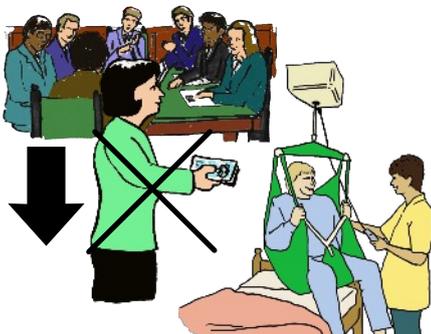
- what different disabilities might mean for the life of a baby



- positive stories of families with a child with disabilities



- that they are the only person who can choose whether to end the pregnancy or not.



Tests should never be a way to end pregnancies so governments spend less care and support for people with disabilities.

Support people to make their own decisions



The Disability Convention says everyone should have the support they need to be involved in decisions. For example, about their health and social care.



Countries should get rid of laws that allow families or other people to make decisions for someone just because they have a disability.



They should also get rid of laws that allow families or doctors to treat or operate on young people with disabilities if they do not agree to this.



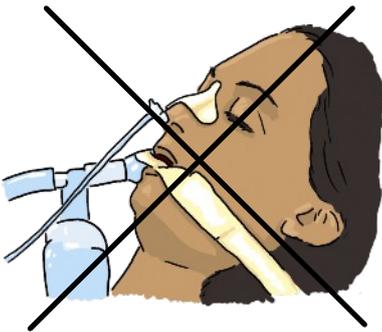
Governments should punish anyone who deliberately harms a person with a disability through science or medicine. They should listen to **victims** and do all they can to make things right for them.



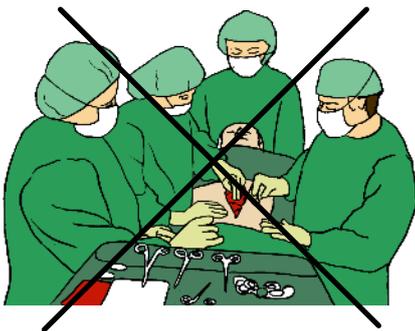
They should have laws and rules to protect people with disabilities with as much support as they need to be involved in decisions. Even if other people do not agree with what they decide.

Protect the right to life

Governments must make sure people are not discriminated against because of their disability when doctors decide:



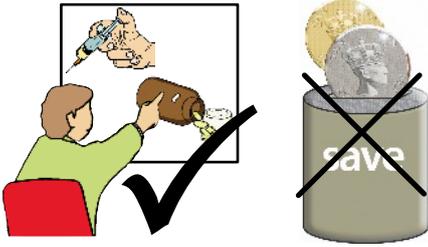
- not to give them treatment to keep them alive



- not to give them an organ transplant



- whether to help them die.



Decisions about treatment must be based on what the person chooses. Not on saving money.



People with disabilities must know how to complain if they think a doctor makes a decision just because of their disability.



Having a disability should not be a reason to help someone die.

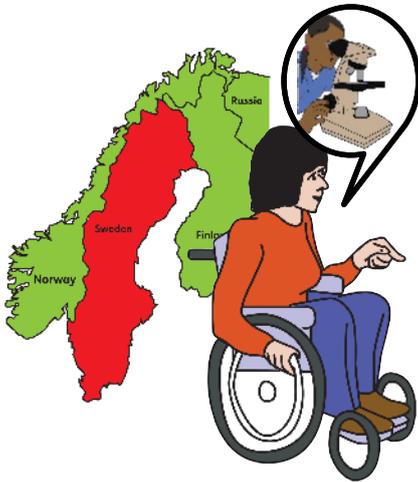


Involve people with disabilities

Governments should involve people with disabilities and their organisations when they think about how new ideas in medicine and science should be used.



This includes women and young people with disabilities.



In Sweden there is a person with disabilities on the committee that decides about bioethics.



Other governments could follow this idea.



But they should remember that these committees are just one way to think about science and medicine.



The most important thing is to think about how new plans, rules and laws could affect the human rights of people with disabilities.



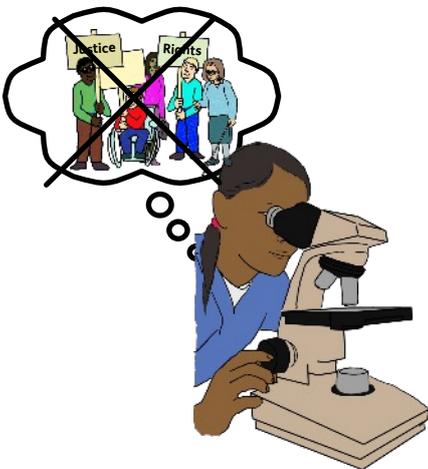
8. What happens next?



The Special Rapporteur found that people all over the world still believe that life is not worth living if you have a disability.



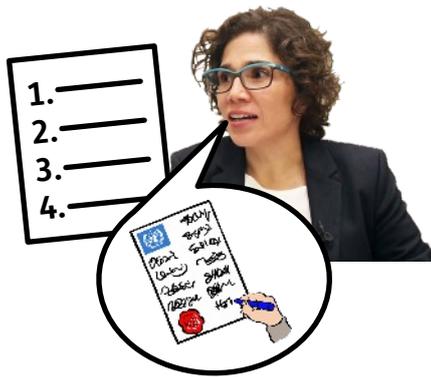
This leads to discrimination and prejudice.



It means people forget about human rights when they decide how to use science and medicine for people with disabilities.



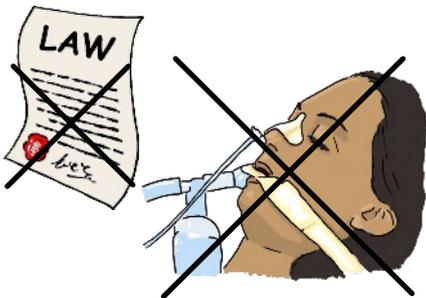
Persons with disabilities contribute to society like everyone else. People need to understand that people with disabilities can lead good lives and have the same chances and experiences as everyone else. As long as they have the support and services they need.



The Special Rapporteur says countries that sign the Disability Convention can change the way people think about disability by doing 4 things:



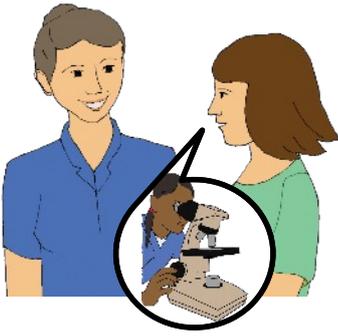
1. Get rid of laws and ways of working that discriminate against people with disabilities. Especially in science, medicine and research.



Get rid of laws that take away a person's right to treatment or care because of their disability.



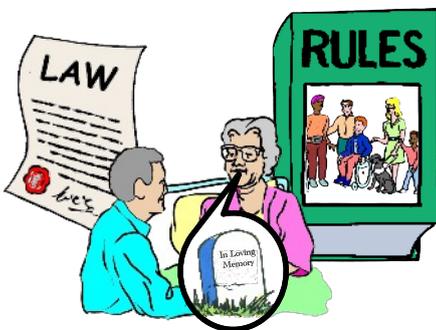
Have laws about supported decision-making with people with disabilities for treatment or research.



2. Protect people with disabilities' right to life and listen to and respect their decisions about research, science and medicine.



Make sure tests for disability are based on human rights for people with disabilities.



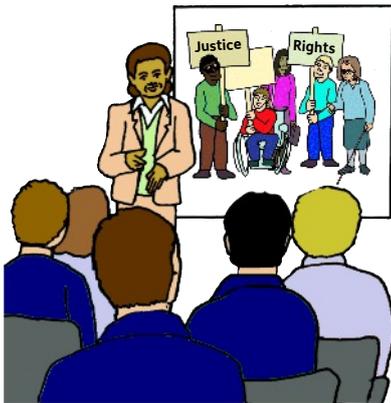
If a country's laws allow assisted dying, make sure there are rules that protect the right to life of people with disabilities.



3. Involve people with disabilities and their organisations in new laws or rules about how science and medicine should be used. This includes bioethics committees.



4. Help other people, services, organisations and the media value and respect people with disabilities.



Train medical and science students about the rights of people with disabilities.



The Special Rapporteur says the international Bioethics Committee must work with people with disabilities and their organisations to include their human rights in all its work.



9. What the words mean

Ableism - When other people discriminate against people with disabilities, think only about what they cannot do and believe they are worth less than people without disabilities.

Abortion – an operation to stop a pregnancy.

Accessible – easy to use.

Assisted dying - when a person asks someone else to help them end their life. For example a doctor might give them medicines. This usually happens when the person has a serious illness and wants to choose when and how they die.

Autism - is a lifelong disability that affects how a person communicates with and relates to other people, and how they understand what is happening around them.

Bioethics - thinking about human rights and how new ideas in medicine, science and research could and should be used.

Dementia – an illness that affects the brain and memory and can make people confused. It gets worse over time and mostly affects older people. But younger people can get it too.

Dignity - that every person is important because they are humans, so they deserve to be treated with respect.

Disability Convention – a set of rules that countries have to follow to give people with disabilities the same human rights as everyone else.

Discrimination – treating someone worse than other people because of who they are or where they come from.

Human Rights – basic rights and freedoms that should happen for every person in the world.

Independent – not being controlled by other people. Being able to do things that you want.

Media – TV, newspapers and radio.

Organ transplant – when doctors take an organ such as a kidney or heart and put it into another person's body because theirs is damaged.

Prejudice – deciding what someone is like without actually knowing them.

Research - a planned and organised way to answer questions and find things out.

Special Rapporteur – a person working for the UN who helps countries understand what they need to do to make sure people get their rights.

Sterilise - an operation that stops women and girls having babies.

Stigma – think badly of someone because of who they are.

Stereotype – when people have a set idea about a group of people or type of person without really knowing them.

Support - help to be involved and do every day things.

Supported decision-making - when supporters help a person with a disability understand, make, and communicate their own choices.

United Nations – a group of 193 different countries that work together to try to make the world a better and safer place for everyone.

Rights – things that should happen for every person.

Victim – someone who is hurt, injured or killed, either by accident or deliberately.



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