

My Body, (but not) My Choice

Legal Capacity Violations Against
Women with Intellectual or Psychosocial Disabilities
and Recommendations for Action



A report by



Acknowledgments

Many organizations worked together on this report.

They are:

- Women Enabled International (WEI)
- Inclusion International
- Transforming Communities for Inclusion (TCI) Global
- The Disability Rights Fund
- Asociación Liber, Spain
- Kenya Association of the Intellectually Handicapped (KAIH)
- Psychiatric Survivors Association of Fiji (PSA)
- Self-Advocates Becoming Empowered (SABE), the United States
- Triumph Mental Health Support (TRIUMPH), Uganda

We also want to thank all the participants who took part in the research for this project.

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Introduction

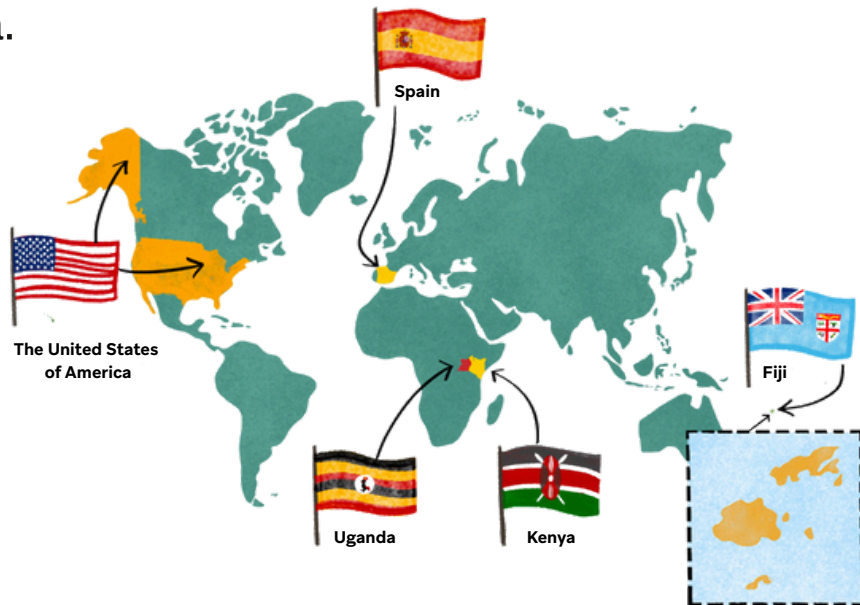
This report is about a project on the right to make decisions about:

- our bodies,
- relationships, and
- having children.



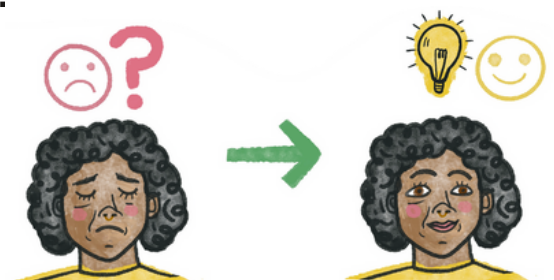
In this project, we did research with women from around the world.

- We talked to women with intellectual disabilities in Kenya, Spain, and the United States.
- We talked to women with psychosocial disabilities in Fiji and Uganda.



We wanted to do this research to learn whether women with disabilities are allowed to make their own decisions about their bodies, relationships, and having children.

We think that learning about these topics helps us figure out how to make things better for women with disabilities.



Methodology

A lot of research about women with disabilities is done without women with disabilities. We wanted to do things differently.



This research followed the

Listen Include Respect Guidelines.

- The Listen Include Respect Guidelines help organizations understand what they need to do to make sure people with intellectual disabilities are included in their work and decision-making.



This research also followed the

Transforming Communities for Inclusion Guidelines.

- The Transforming Communities for Inclusion Guidelines help organizations understand what they need to do to make sure people with psychosocial disabilities are included in their work and decision-making.



Methodology

102 adult women with intellectual or psychosocial disabilities took part in the research for this project through focus groups or interviews.



The women were all paid money for taking part in the focus groups or interviews and sharing their experiences.



Women with intellectual or psychosocial disabilities led the focus groups and interviews.



This report is about what we learned in the focus groups and interviews.



Understanding Our Human Rights

This project is about different human rights.



1. The right to legal capacity. This is the right to make our own decisions.

- All adults have the right to make their own decisions.



- In some countries, there are guardianship laws. These laws mean someone else can legally make decisions for us, even if we do not want them to.



- The right to make our own decisions is violated when someone else makes decisions for us.



Understanding Our Human Rights

2. The right to sexual and reproductive health and rights.

This means we have the right to do many things, like:

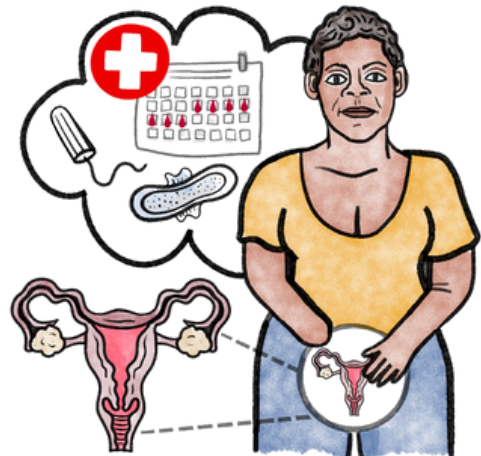
- Make decisions about our bodies, relationships, and having children.



- Get information about our bodies, relationships, and having children in ways that we can understand.



- Get healthcare that keeps our genitals and reproductive systems healthy.



The right to legal capacity and our sexual and reproductive health rights are in the Convention on the Rights of Persons with Disabilities (CRPD).

Governments are supposed to do what the CRPD says. But this does not always happen.

Global Findings

Overall, through our research, women told us that:

They do not always get to make decisions about their own bodies, relationships, and having children.



Sometimes, doctors, family, or other people in their lives make these decisions for them.

Sometimes, someone else pressures them to make decisions they do not want to make.



Women usually are not given enough information to make their own decisions about their bodies, relationships, and having children.



All these things violate our human rights.

There are 6 big things that we learned about the right to make decisions about our bodies, relationships, and having children.

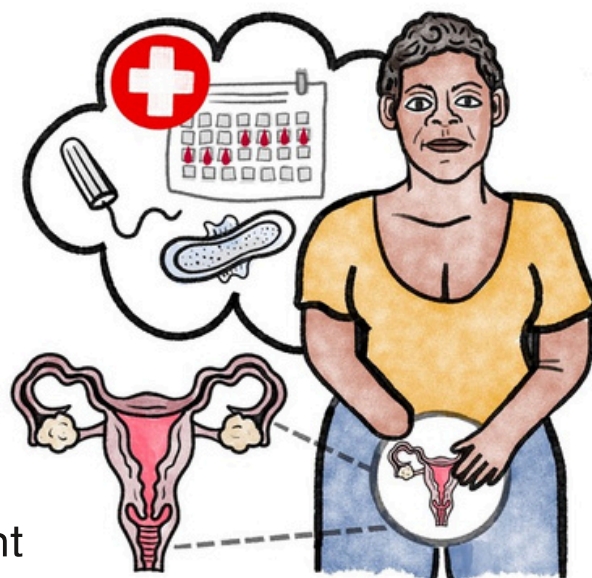
Global findings

1 Making decisions about our health

Sexual and reproductive healthcare means healthcare that keeps our genitals and reproductive systems healthy.

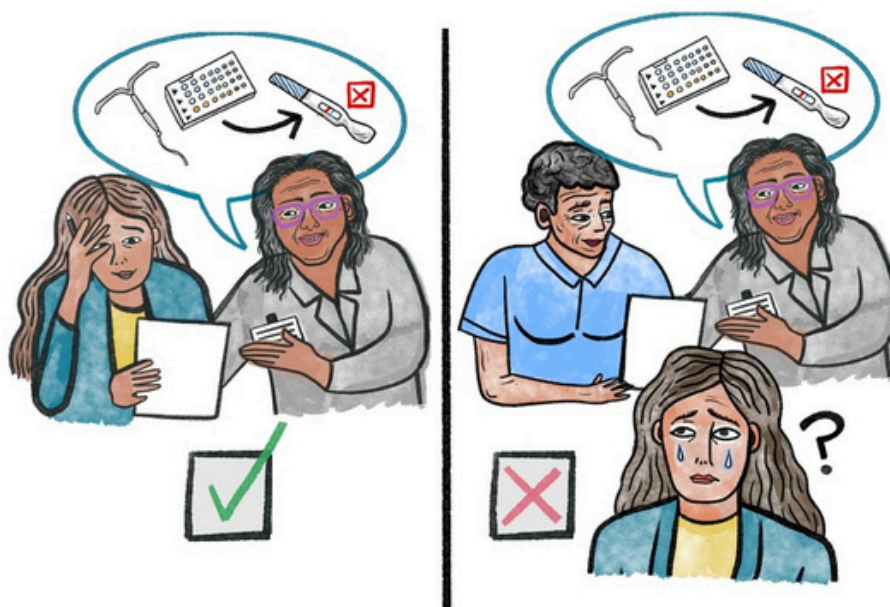
This could include things like:

- Treatments for problems like painful periods
- Whether to take medicine like birth control pills to avoid getting pregnant



Many women are stopped from making their own decisions by healthcare providers, like doctors or nurses.

Sometimes, healthcare providers do not talk with women about their own healthcare. They will talk to someone else, like a support person or family member, instead.



Global findings

1 Making decisions about our health

A woman with an intellectual disability in the **United States** said: “I am my own guardian; I have always been my own guardian...And [the hospital] treated me terribly in this department...They kept treating me like I wasn't my own guardian, kept asking my [support person] stuff...”



Some people think that women will be healthier if other people make healthcare decisions for them.

But it does not make women healthier.

When other people make health decisions for women, it can mean that women do not get sexual and reproductive healthcare at all.



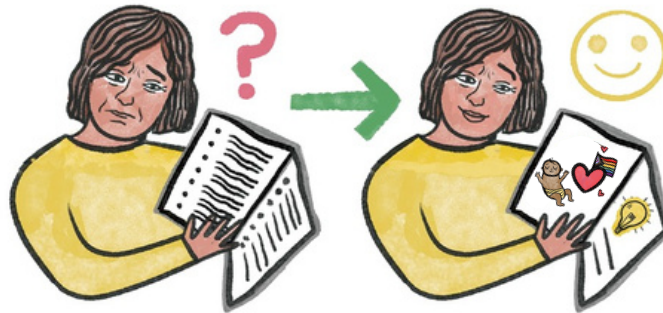
A woman with a psychosocial disability in **Uganda** said:

“I know and see the need to go for checkups, but it is not taken as important to my family to access the health services related to my health as a woman.”

Global findings

2 Getting information about our rights, bodies, and relationships

We all need information about our rights, bodies, and relationships to be able to make decisions.



Many women with intellectual or psychosocial disabilities get this information from other people, like family members or service providers.



Sometimes, people only give women information from one point of view.

For example, some people only tell women the bad things about relationships and having sex.



People might do this because they think that women cannot understand things like relationships or having sex.

Or because they think that women should not do things like be in relationships or have sex.

Global findings

2 Getting information about our rights, bodies, and relationships

Families might be scared that women will get hurt if they try to be in a relationship or have sex.

Sometimes, doctors make families feel this way.

There are many doctors who have told families to limit the information they give to women with disabilities.



A woman with an intellectual disability in **Spain** said: “In high school, my older sisters told me to be careful because boys would take advantage of me and get me pregnant.”

Some people do not give women any information at all.

This makes it very hard to make decisions.



This happens a lot to women with high support needs and to women who use different ways to communicate, like assistive technology.



Global findings

3 Making decisions about pregnancy and being parents

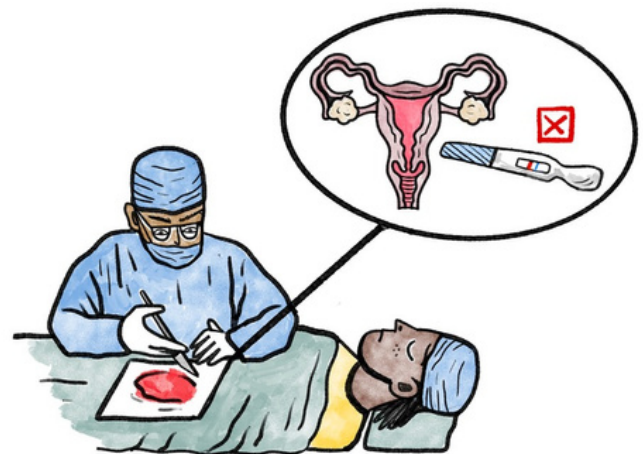
Many women with intellectual or psychosocial disabilities are told they are not allowed to have children.



A woman with an intellectual disability in the **United States** said: “My dream was always to have a baby, but my mom still doesn’t think I’m ready. So, I’m not going to do it.”

Some women are told they have to be **sterilized**.

Sterilization is a procedure that changes a person’s body so that they cannot ever get pregnant.



Some women are told they have to use **contraception**.

Contraception means medicine that stops people from becoming pregnant for a period of time, like birth control pills or intrauterine devices (IUDs).



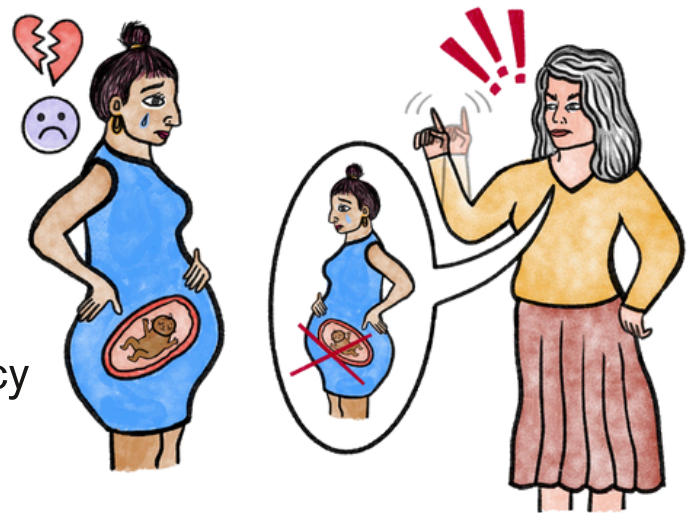
Global findings

3 Making decisions about pregnancy and being parents

Some women are pushed to have an **abortion** if they get pregnant--even if they want to have a baby.

An abortion can be medicine or a procedure that happens when someone is pregnant.

An abortion ends a person's pregnancy so that they will not have the baby.



A woman with an intellectual disability in **Kenya** said:

"There was a time I got pregnant, [and] my mother made me have an abortion...[When] I lost my child, I was really hurt."

When women do have children, sometimes they are not allowed to make decisions about their children's lives.

And sometimes their children are taken away from them because of their disability.



A woman with a psychosocial disability in **Fiji** said:

"My ex-husband used [my disability] in court to take away one of my children. I felt helpless and hopeless."

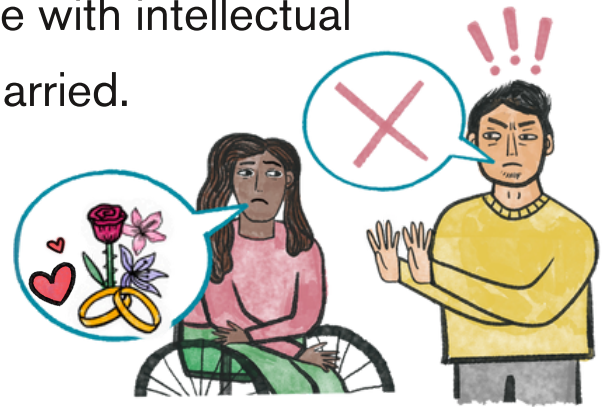


Global findings

4 Making decisions about getting married

Many countries have laws that say people with intellectual or psychosocial disabilities cannot get married.

Even if laws allow it, many women are told that they are not allowed to get married.



A woman with an intellectual disability in **Kenya** told us how her mother has stopped her from getting married, explaining that “she just refuses.”

Some people think that women are only good wives if they do things like cook and clean.

So, some people think that women with disabilities cannot be wives because they may need support to do those things.



Women may hear these things so often that they start to think this too.

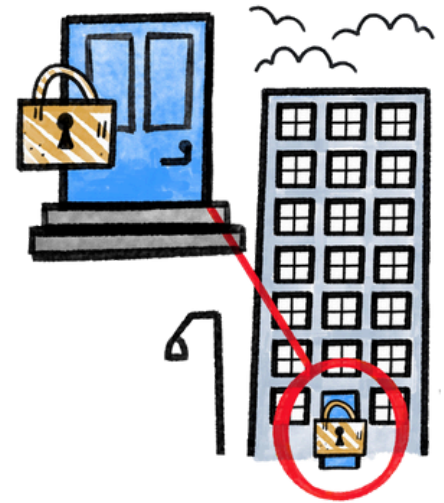
A woman with an intellectual disability and a wheelchair user in **Spain** told us that she dreams about getting married. But other people have made her feel like she cannot. “People asked me, ‘How can you get married? Do you know how to cook? Can you take a shower by yourself?’ I think about it, and they are right.”

Global findings

5 Institutions and decision-making

An **institution** is any place where people with disabilities:

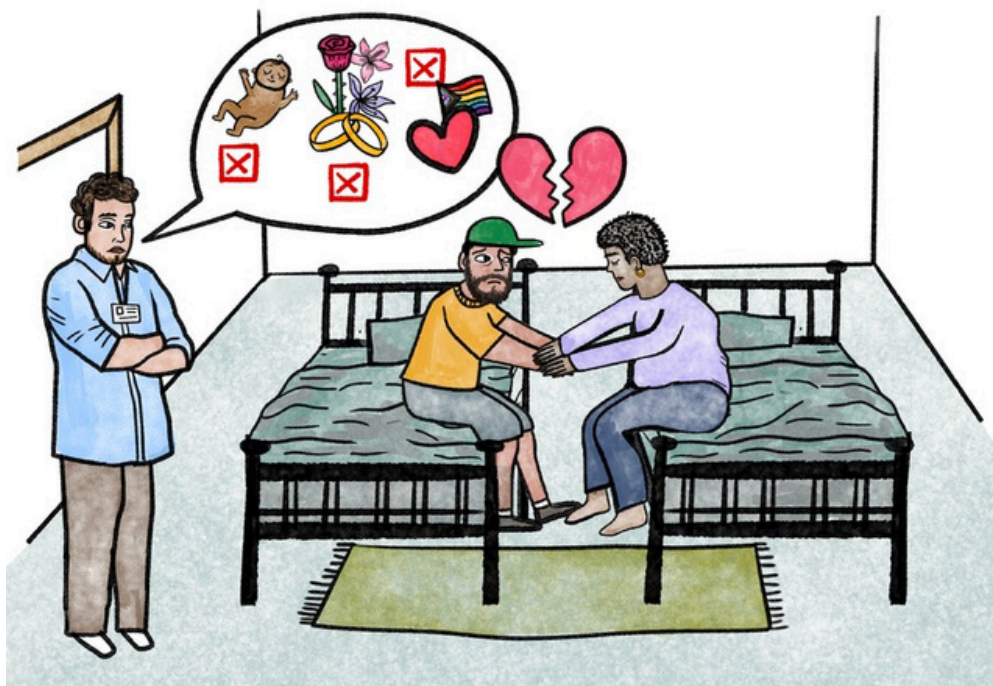
- Are separated from the community
- Live together in groups
- Do not have control over their day-to-day decisions



Institutions can be large or small.

Many women who live in institutions do not get to make their own decisions about their bodies and their relationships because of rules that say the people who live there are not allowed to:

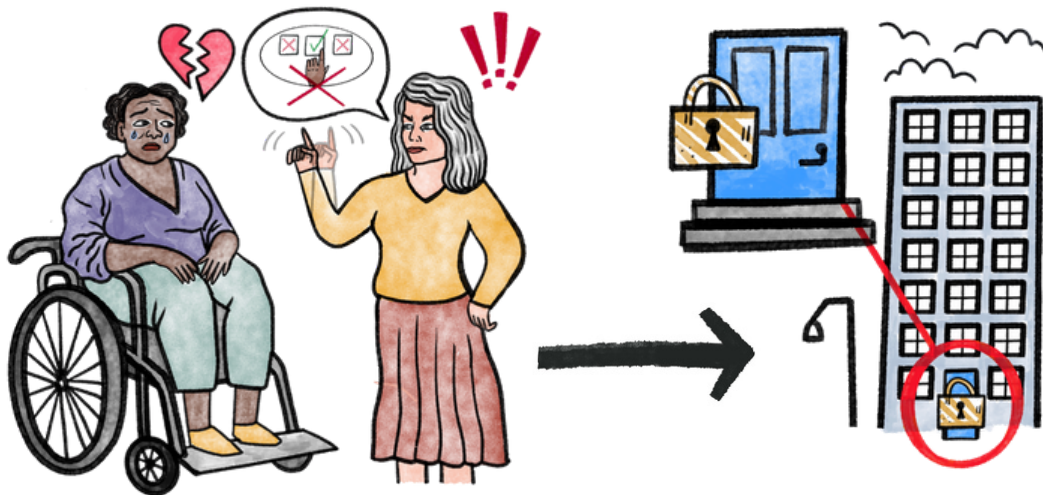
- Start a family
- Get married
- Spend time alone with their romantic partner



Global findings

5 Institutions and decision-making

Sometimes, people will make women live in institutions to stop them from making their own decisions about relationships.



This may happen more to LGBTQIA+ people. For example, women who want to be in relationships with other women.



A woman with a psychosocial disability in **Fiji** told us that her parents threatened to send her back to an institution because she liked a woman at her church. She explained, “My mom and dad stopped me from liking anyone. They said they would call [the institution], and I would be sent back there if I liked someone.”



Global findings

6 Gender-based violence and decision-making

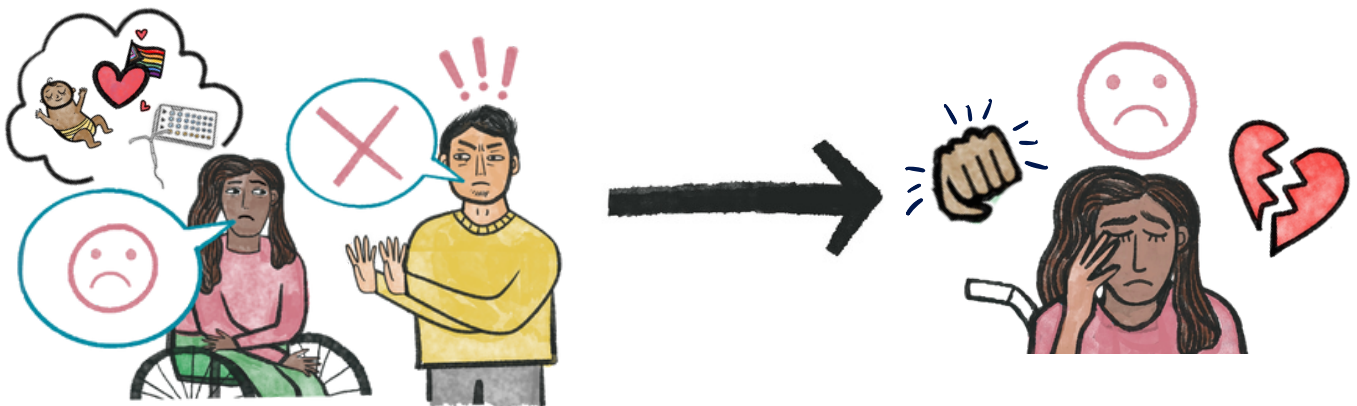
Gender-based violence is any violence against someone because of their gender.

Gender-based violence can be sexual. For example, rape.

Gender-based violence can also be physical, emotional, or economic.



When women are not allowed to make their own decisions about their bodies and their relationships, they may be more likely to experience gender-based violence.



This could be because:

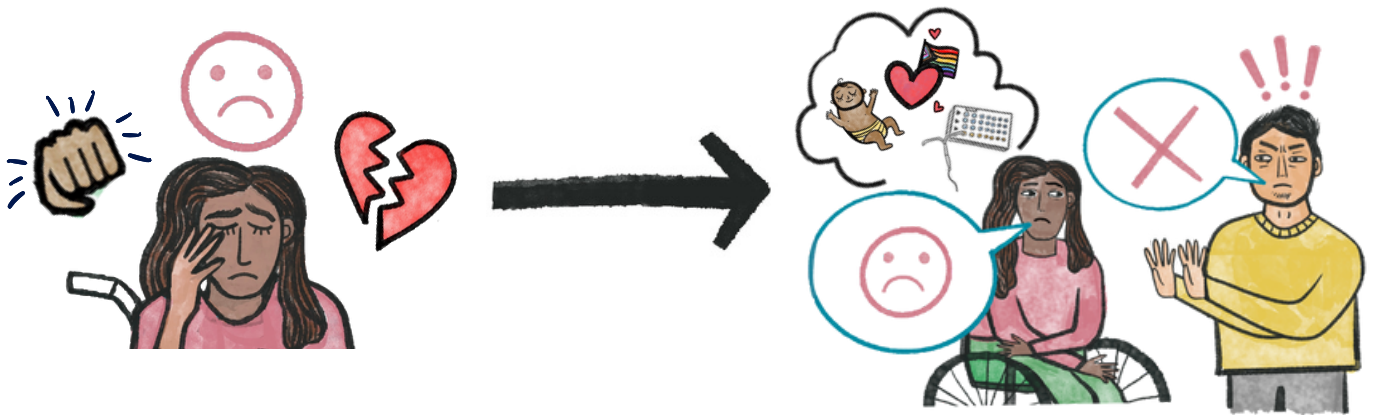
- Women may not get important information about what gender-based violence is or how to report it.
- Women may think that they have to say “yes” whenever someone tells them to do something.



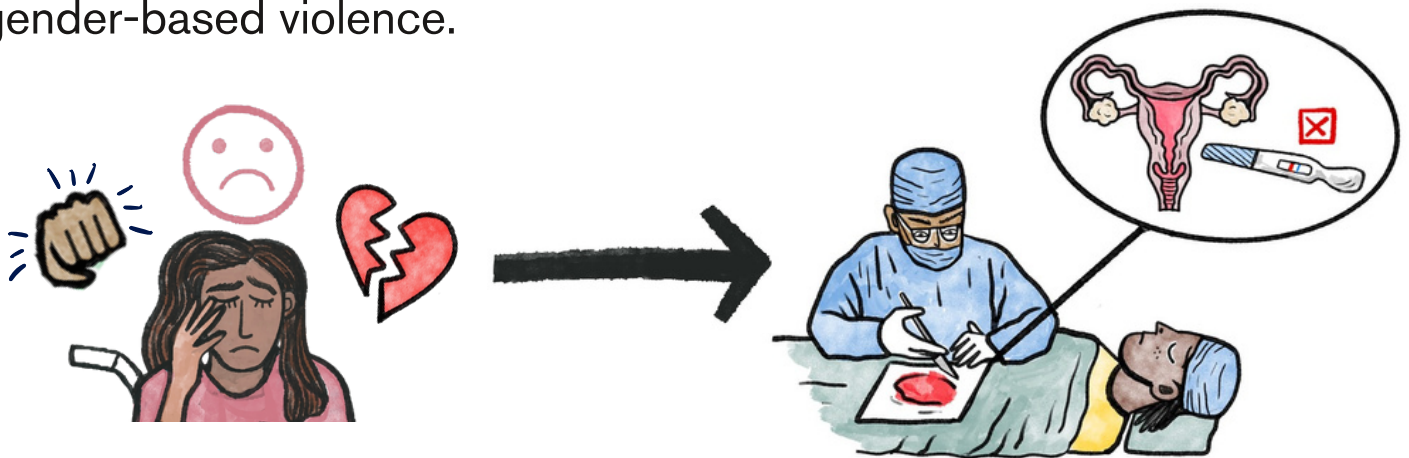
Global findings

6 Gender-based violence and decision-making

And sometimes, women are stopped from making their own decisions after they experience gender-based violence.



For example, some women are told they have to be **sterilized** after gender-based violence.



Sterilization is a procedure that changes a person's body so that they cannot ever get pregnant.

A woman with an intellectual disability in **Spain** told us her mom made her get sterilized after she was raped.

She said, "I didn't want [to be sterilized], but to obey my mother, I had to do it."

Country-Specific Findings

The 6 big things we learned were problems in many countries. But there were also some problems that women with disabilities in only one country told us about.



This was usually because there is something different about where they live that changed their experience.

For example:

In **Fiji**, women who lived on smaller islands far away from big cities got less information about their bodies, relationships, and having children than women in big cities.



In **Kenya**, some women said their families would only let them leave home to go to work.

They said they depended on their families for money.



This made it hard for women to make their own decisions about their bodies, relationships, and having children.

Country-Specific Findings

For example:

In **Spain**, women told us that even though Spanish laws changed to make it so that you cannot be put under guardianship anymore, women still do not get to make their own decisions.



In **Uganda**, some women told us that they never want to visit a doctor again.

This is because doctors had stopped them from making their own decisions before.



In the **United States**, some women may have been stopped from making their own decisions about their bodies because of **racism**.

Racism is the harmful idea that people with some skin colors are better than people with other skin colors.

Racism is when someone is treated badly because of their skin color.



Recommendations

We learned many things from this research.

These are some recommendations based on what we learned:

1

Change guardianship laws to laws that help women get the support they want to make their own decisions, like supported decision-making.



2

Help people, like doctors and families, understand the right to make decisions.

We also need to help people learn how to support women in making decisions about our bodies, relationships, and having children.



For example, how to use supported decision-making.

3

People working on sexual and reproductive health and rights should talk about the right to make decisions.

And people working on the right to make decisions should talk about sexual and reproductive health and rights.



Recommendations

4

Close institutions. Institutions violate our human rights for many reasons.

One reason is that they are places where women cannot make their own decisions.



5

Make more information about our bodies, relationships, and having children in ways that we can understand.

We also need to make it easier for women to get this information on their own.



6

Do more research about gender-diverse people with disabilities and their right to make decisions about their bodies, relationships, and having children.



- We wanted to include gender-diverse people in this research. But only one gender-diverse person took part in the research.
- So, this report only talks about women. That is why it is important to do more research.