

With help from the Autistic Women & Nonbinary Network

## FORCED STERILIZATION OF DISABLED PEOPLE IN THE UNITED STATES

### **PLAIN LANGUAGE**

We wrote this report in Plain Language. Plain Language is a style that is more accessible to many people. These include some people with intellectual disabilities. Forced sterilization happens to people with intellectual disabilities more than anyone else. And people with intellectual disabilities have important things to say about forced sterilization.

Everyone should get to understand information about issues that affect them. But nondisabled people often talk about forced sterilization in a way that leaves out people with intellectual disabilities. Using Plain Language helps change that.

## **IDENTITY-FIRST LANGUAGE**

In this report, we usually say "disabled people" instead of "people with disabilities." This is called identity-first language. Many disabled advocates like identity-first language better. You can find more about identity-first language <u>here</u>. But we also say "people with intellectual disabilities." This is how many people with intellectual disabilities like to describe themselves.

## WHAT TO EXPECT

A lot of this report will talk about times when judges, doctors, family members, and other people hurt disabled people. This will include talking about sexual violence. Sexual violence is when someone gets hurt in a sexual way.

This report uses information from laws and court decisions. Some of these laws and decisions use hurtful language about disabled people.

Sometimes it is hard to read about these topics. You might want to take breaks while reading this report. You can ask someone you trust to check on you while you are reading. You might want to wait until you feel okay before you read more.

## **THANK YOU**

The National Women's Law Center wrote this report with help from the Autistic Women & Nonbinary Network.

Thank you to everyone who helped us with this report. Max Barrows, Lydia Brown, Sam Crane, Tia Nelis, and Karen Willis reviewed this report. The law firm Covington & Burling LLP helped with research.

## DISABLED PEOPLE HAVE FOUGHT TO MAKE THEIR OWN DECISIONS FOR MANY YEARS.

They have fought to make decisions about their bodies and having babies. But many laws still take that decision away from them. These include laws about sterilization.

Sterilization is an operation or procedure that stops someone from ever having babies. Disabled people should get to decide if they are sterilized or not. But in some cases, laws say that a doctor can sterilize a disabled person even when that person does not want it. **This report is about laws that let doctors sterilize disabled people against their will.** 

Some people think that forced sterilization only happened in the past. But most states have laws that allow forced sterilization today. These laws exist in 31 states plus Washington, D.C.

We do not know how many disabled people get sterilized under these laws. When disabled people are forced to be sterilized, they do not always get to share their story with the world. This report is about one part of the story: **the laws that let forced sterilization happen.** 

## WHAT IS FORCED STERILIZATION?

One type of sterilization is tubal ligation. It is also called "getting your tubes tied." Another type of sterilization is a hysterectomy. A hysterectomy also stops someone from having periods.

Sometimes people want to be sterilized. People might want to be sterilized because they know they do not want babies. If someone wants a sterilization, they should be able to get it. No one should make it hard for them. The important thing is that they are making the decision.

## Sterilization is an operation that stops you from getting pregnant or having

**babies.** Sterilization is supposed to be permanent. So if you get sterilized, you usually cannot undo it.

## Here are a few facts about disabled women and sterilization:

- Women with intellectual and developmental disabilities get sterilized more than nondisabled women.
- They also get sterilized when they are much younger than nondisabled women.<sup>1</sup>
- Black disabled women are more likely to be sterilized than white disabled women.<sup>2</sup>

There are many reasons why disabled women, especially disabled women of color, are sterilized more. Sometimes people want to be sterilized. Sometimes it is more complicated. Some people are worried they do not have enough money for children. Some people have problems getting other types of **birth control** (other ways to avoid getting pregnant). Sometimes people are pressured to make the decision. These things happen more to disabled women and women of color.

## LINDA'S STORY

Linda Kay Sparkman was a 15-yearold with an intellectual disability. Linda's mother asked a judge for

Linda's mother asked a judge for permission to get Linda sterilized. The judge agreed that sterilization was a good idea.

No one told Linda she was going to be sterilized. The doctors told her she was getting a different operation. Linda tried to have a baby a few years later. That is when she found out that she was sterilized.<sup>3</sup>

### NATIONAL WOMEN'S LAW CENTER

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## **ASHLEY'S STORY**

Ashley X is a woman living in Washington. She is now in her 20s. When she was 6, her parents asked doctors to do a hysterectomy. They did not want her to get pregnant or have periods. They also wanted her to stay small like a child for the rest of her life. So doctors did a hysterectomy. They gave Ashley drugs that stopped her from growing. They also did an operation to stop her from having breasts.

These procedures are now called the "Ashley treatment." Many other parents have made their disabled children get the "Ashley treatment."4

Sometimes people do not want to be sterilized, but it happens anyway. This is forced sterilization. Forced sterilization is when doctors sterilize someone even though they did not agree.

## Here are some examples of forced sterilization:

- going to be sterilized.
- you want to be or not.
- for you, like a judge, a family member, or a guardian.<sup>5</sup>

If a person did not agree to be sterilized, the sterilization is a forced sterilization. It is a forced sterilization even if someone like a parent or guardian gets permission from a judge first. And it is a forced sterilization even if the parents or guardians think it is for the disabled person's own good.

photo: pexels

You get sterilized even though no one told you that you were

You get sterilized without getting a chance to say whether

▶ You get sterilized when another person makes the decision

Many disabled people want to have children. But even if they do not want children, they should be able to make their own decision. Some people say that forced sterilizations are not bad, because they help disabled people. They say that sterilization means a person does not need to worry about getting pregnant and having children.<sup>6</sup>

But taking away this choice can hurt disabled people for the rest of their lives.<sup>7</sup> For some disabled people, knowing you can never have a baby hurts a lot. And if someone changes your body in a big way without your permission, that can be very upsetting. It can change how you feel about yourself and other people for many years.

## WHAT IS A GUARDIAN?

A **guardian** or a **conservator** has the power to make decisions about someone else's life. If a judge thinks you cannot make your own decisions, the judge might say you need a guardian. Most people with guardians are disabled.

People who have guardians lose many of their rights. They sometimes lose their right to get married, vote, and take care of their children. Many times, guardians can decide for them where they live, who they can be friends with, and how to spend their money. There are a lot of problems with guardianship.

Many guardians can decide what health care someone gets. Usually the guardian does not need to ask a judge first.<sup>8</sup> For example, if the guardian wants you to go to the dentist, the guardian can make you go without asking a judge. But sterilization is different. Guardians usually need special permission from a judge before they can get you sterilized.<sup>9</sup>





# FORCED STERILIZATION LAWS

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> men disal **Toda D.C.**

Two states (Alaska and North Carolina) ban forced sterilization in most cases. This sounds like a good thing. But these laws also stop some disabled people who want a sterilization from getting one. This is not the right answer to the problem. Disabled people should get to make these decisions for themselves.

Forced sterilization happens all over the world. In many countries, there are laws that let it happen. These countries include the United States.

Laws in many U.S. states say that a disabled person can sometimes be sterilized even if they do not agree to it. These laws let judges, along with other people like guardians or family members, make the decision for the disabled person.<sup>10</sup>

## Today, 31 states plus Washington, D.C., have laws allowing forced sterilization.

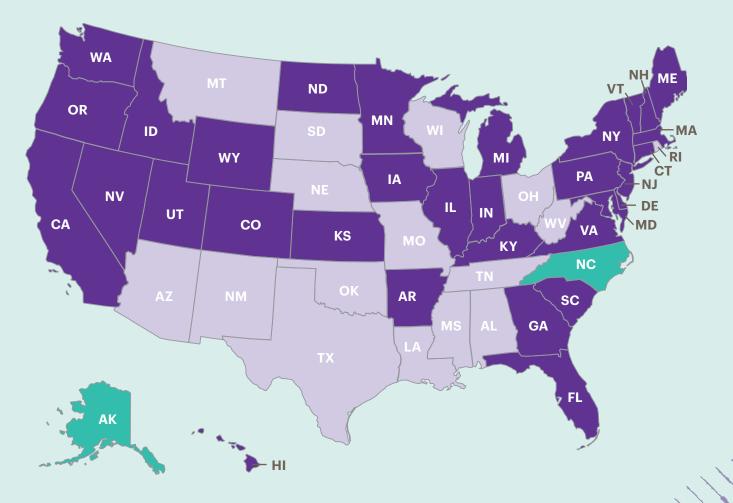
The rest of the states and territories do not have laws about forced sterilization. In most of these states, it is not clear if the law allows forced sterilizations.<sup>11</sup> In these states, we do not know for sure what a judge would do if someone asked for a forced sterilization.

In states that do not have laws, forced sterilizations might still be happening to people under guardianship. This is because many guardians have a lot of power to make health care decisions for people under guardianship. They usually do not need to ask a judge before deciding what health care someone gets. In states that do not have forced sterilization laws, some guardians might be treating sterilization like any other type of health care. They might decide to have someone sterilized without asking a judge first. So judges in these states might not even know about it when it happens.

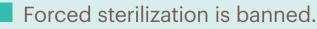


## STATES THAT ALLOW FORCED STERILIZATION

This map shows the states that allow forced sterilization. The list of states and their laws is in the document called "Forced Sterilization Laws in Each State and Territory."



Forced sterilization is allowed.



It is not clear if forced sterilizations are allowed.\* \*Includes Puerto Rico, Guam, and Virgin Islands

## Today, 31 states plus Washington, D.C., have laws allowing forced sterilization.

# FORCED STERILIZATION IN THE PAST

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Today's forced sterilization laws started in the 1970s and 1980s. But forced sterilization happened a lot before then, too. This section is about forced sterilization that happened before today's laws existed.

In the beginning of the 1900s, states started to pass new laws. These laws said that the government can force some people to be sterilized. These laws are different from the laws that we talk about in the rest of this report. The old laws were part of the eugenics movement.<sup>12</sup>

The **eugenics movement** is a group of people who want to control who has babies. People who supported eugenics have tried to stop disabled people and people of color from having babies. They thought disabled people would have disabled babies, and they thought that that was a bad thing. They wanted there to be no more disabled people in the future. And they thought that white people were better than people of color. They wanted there to be fewer people of color in the future, too.



Under the old eugenic laws, states forced almost 70,000 people to be sterilized.

forced sterilization.

Under the eugenic laws, states sterilized almost 70,000 people. That included many disabled people. It also included people who were poor and people who were in prison or jail.<sup>13</sup>

Eugenic laws especially targeted women of color. This included Black women, Latina women, and Native women. Many powerful people, like doctors and people in the government, supported these laws. They thought it would be better for society if women of color did not have children. They did not want more people of color to be born. They thought that women of color could not make good decisions about having children or take good care of their children.<sup>14</sup> Doctors and people in the government used these beliefs to sterilize many Black, Latina, and Native women against their will.

## Most people today say they do not support eugenics. But in the beginning of the 1900s, the eugenics movement was very popular. It was so popular that 32 states passed laws allowing

People asked the Supreme Court if there was any problem with these laws. The Supreme Court is the most important court in the country. It has the final say on many questions about laws. In 1927, in a case called Buck v. Bell, the Supreme Court said that these laws were allowed. It said that forced sterilization can be legal as long as people followed enough rules before the sterilization happened. For example, if someone was going to be sterilized against their will, they needed to have a chance to tell a judge why they did not want to be sterilized.

The Supreme Court even thought that these laws were a good thing. It said that people being sterilized probably would not be able to take care of themselves and their children.<sup>15</sup> Many people now think this was a bad decision. But the Supreme Court has never said that the decision in Buck v. Bell was wrong.

Today, most of the sterilization laws from the eugenics movement are gone. There are a few states that never got rid of their laws. But even those states do not use these laws anymore. That does not mean that the eugenics movement has gone away. But it means that the laws from the early 1900s are not being used anymore.

But that was not the end of people being forced or pressured to be sterilized. Many people still believed that disabled people should not have children. And they still did not want more people of color to be born. So they believed it was okay for the government and doctors to take the decision away from disabled people and women of color. For example, in the 1960s and 1970s, the government and doctors pressured or forced thousands of Native, Black, and Latina women into being sterilized.<sup>16</sup>

This is still happening today. There are many recent examples when people were forced or pressured to be sterilized. This has happened in places where there are a lot of disabled people, especially a lot of disabled women of color. These places include prisons and jails.

For example:

- in prison in California.<sup>17</sup>
- telling them that they would get less jail time.<sup>18</sup>
- Until 2020, a doctor pressured or forced women to get



Between 2006 and 2010, doctors sterilized almost 150 women

Some judges have pressured people into getting sterilized by

sterilized in an immigration detention center (a type of prison where the government forces some immigrants to stay).<sup>19</sup>

# TODAY'S FORCED STERILIZATION

In the 1970s, many states were getting rid of their eugenic sterilization laws. These laws were not as popular anymore. But people still thought that some disabled people should be sterilized. And lots of people still believed in eugenic ideas, even if they did not use that word. So states began passing a new type of forced sterilization law. This kind of law lets a judge decide whether to sterilize someone who

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This kind of law lets a judge decide whether to sterilize someone who cannot give consent. Being able to give consent (or permission) means you understand what sterilization is and you can say yes to it. Under these laws, a judge decides if you can give consent. If the judge thinks you do not understand sterilization or cannot say yes to it, the judge can make the decision for you.<sup>20</sup> These laws did not stop in the 1970s. States are still passing new laws today. The last states that passed forced sterilization laws were lowa and Nevada—both in 2019.<sup>21</sup>

The old eugenic laws are mostly gone, but most states still have this new type of sterilization law. People who supported this new type of law said that it was different from the old eugenic laws. They said the old eugenic laws tried to stop more disabled children from being born, but this new type of sterilization law is trying to help disabled people.<sup>22</sup> But these laws are still based on harmful ideas about disabled people. And they still try to control who gets to make decisions about their lives and their families.

# The last states that passed forced sterilization laws passed them in 2019.

## **KIRSTEN'S STORY**

Kirsten Johnson is from Matteson, a city in Illinois. She wanted to be a mother. She said, "Just like my mother took her time taking care of me, I would love to have the opportunity to take my time taking care of a baby." Kirsten also said, "I want to have children because...I will love taking care of them, I will love, you know, to see how they grow... just all the things that, you know, any person would want to have a child."

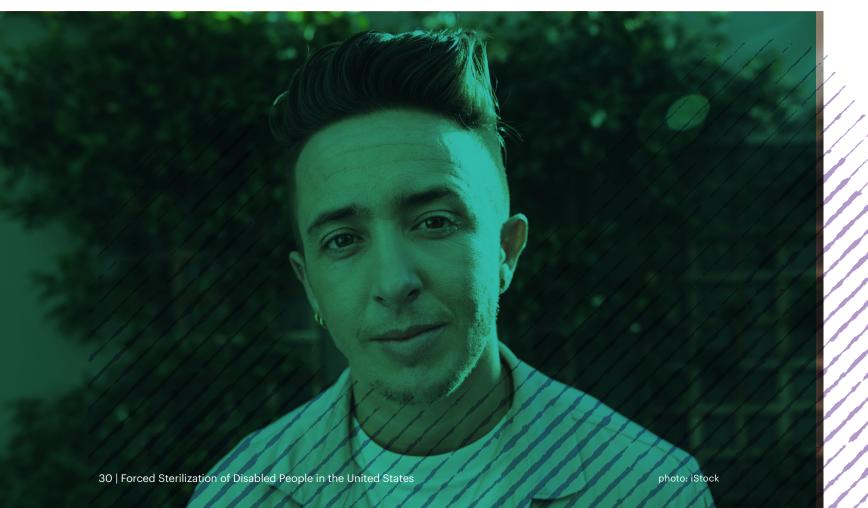
But Kirsten's guardian asked the court to make Kirsten get sterilized. The guardian thought that being a mother would be too hard for Kirsten. Kirsten worked with advocates in Illinois to fight back. In 2008, she won, and she did not get sterilized.<sup>23</sup>

photo: iStock

There are a few reasons why people might think that being sterilized would help a disabled person.

## Here are some examples:

- Some people think that being pregnant or having children might be too hard for that disabled person. Being disabled does not mean you cannot be a good parent. But some people assume disabled people's lives would be easier if they cannot have babies.
- Some people think that if disabled people are sterilized, they will not be forced to have sex. Many disabled women are forced to have sex or are hurt sexually in other ways. This is a serious problem. But sterilization does not solve this problem. Sterilization does not make sexual violence happen less.<sup>24</sup>



- decisions that other people do not like.
- Sometimes people say that a hysterectomy could help they might not know why they are bleeding. And some

People who support these laws might want to help disabled people. But the laws take away disabled people's choices. They are part of a long history of the government making forced sterilizations possible.

Some people think that disabled people are irresponsible and make bad decisions. They say disabled people will rush into having sex without planning. They think disabled people will get pregnant without meaning to. So they think disabled people should not get to make that decision themselves. But getting pregnant without meaning to does not mean that someone was irresponsible or made a bad decision. And everyone should be able to make their own decisions about having sex and getting pregnant. That includes making

disabled people. A hysterectomy is a type of sterilization that also stops you from having periods. People think that some disabled people will get upset if they have periods, because people think that periods are messy and cause problems.<sup>25</sup>

# WHO-DO THESELAWS AFFEC

But there are still a lot of court cases that are not secret. Here is what they tell us:

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We do not know a lot about who gets sterilized under these laws. Usually, a judge makes a decision about forced sterilization in secret.<sup>26</sup> No one has to keep track of these decisions. For example, we do not know if forced sterilizations happen to people of color more or less than white people.

These laws affect mostly people with developmental and intellectual disabilities. They also affect people with disabilities related to mental health.

Forced sterilization happens mostly to people who can get pregnant and have periods.<sup>27</sup> People who do not get pregnant (such as most men) can also be forced to get sterilized under these laws. But when people say that sterilization will fix problems for a disabled person, those problems usually have to do with getting pregnant or having periods. So people who can get pregnant are sterilized more.

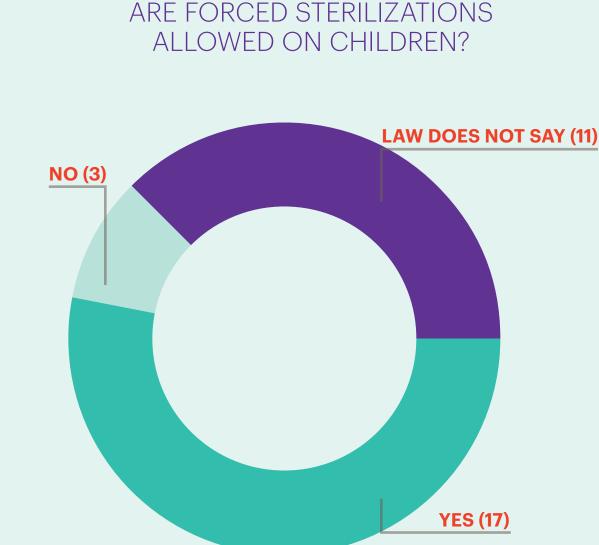
These laws affect both adults and children. Some states allow forced sterilizations on disabled children (people under the age of 18) and some do not.

- 3 states ban forced sterilizations on disabled children.
- ▶ 17 states say that it is allowed.
- ▶ 11 states and Washington, D.C., do not say anything about it.<sup>28</sup>

And these laws affect both people who are under guardianship and people who are not. Remember that a guardian is someone who is allowed to make decisions for a disabled person. If you are "under guardianship," that means that a court has picked someone to be your guardian.

Different states have different rules about guardianship<sup>29</sup>:

- About half the states say that forced sterilization is only for people who are already under guardianship. This means that you already need to have a guardian before a judge decides whether to sterilize you. The guardian is usually the person who asks the court to sterilize you.
- In the other states, you do not need to be under guardianship. In these states, many different people can ask the court to get you sterilized, not just a guardian. These people might include a family member, a doctor, a social worker, someone running a hospital or institution, or someone from the government.<sup>30</sup>



This chart shows how many states and territories allow forced sterilization on disabled children. It is out of the 31 states plus Washington, D.C., that have forced sterilization laws.

# HOW-DO FORCED STERIL ZATION AWSWORK?

But in this case, Herman thinks ljeoma cannot give consent. Herman wants the sterilization even though ljeoma has not said yes. That means that this is a forced sterilization. A judge has to give permission before a forced sterilization happens.

What happens next depends on where Ijeoma and Herman live. The details are different in each state. Some states have long laws that explain all the steps. In other states, the laws just say that judges can allow forced sterilizations. And in some states, there are no laws, but judges decided that they have the power to order forced sterilizations.<sup>31</sup>

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Let's imagine this: Ijeoma is a disabled woman. Her father Herman wants to sterilize her. But Herman thinks ljeoma does not understand what sterilization is. He thinks she cannot say yes or no to it. That means Herman thinks ljeoma

cannot give consent to sterilization.

Usually when someone gets sterilized, a judge does not get involved. If you want to be sterilized, the doctor does it without asking a court. The doctor just needs to know that you can give consent.

But there are many ways states are alike. Here is the most common process:

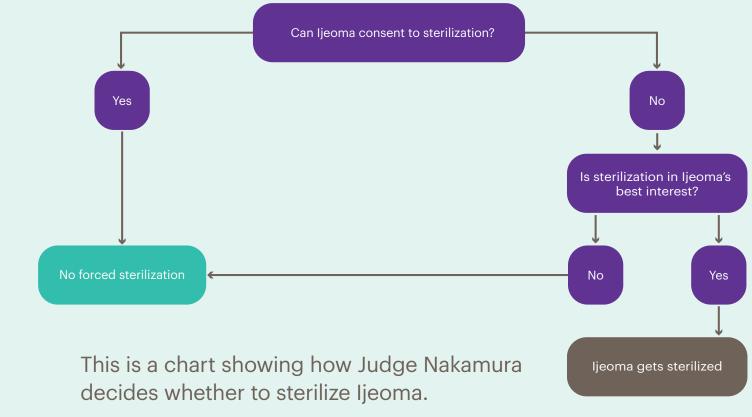
- **1.** Herman asks a judge to sterilize lieoma.
- 2. The judge decides if Ijeoma can give consent on her own. If the judge thinks lieoma cannot consent, the judge makes the decision for her.
- 3. The judge decides if sterilization will help ljeoma (if it is in her best interests).
- 4. And if the judge thinks it is in Ijeoma's best interests, Ijeoma gets sterilized.

## **CAN IJEOMA GIVE CONSENT?**

Let's say the judge's name is Judge Nakamura. The first question Judge Nakamura asks is whether ljeoma can give consent. This means that Ijeoma understands sterilization enough to make her own decision.<sup>32</sup>

Disabled people can make their own decisions about sterilization if they get the right support. For example, some people might need the doctor to explain sterilization in a different way. Some might need tools to communicate what they want. But in most states, the judge does not need to make sure disabled people get this support. Sometimes the judge says that the person cannot give consent. But in reality, that person just might not have gotten the support they needed.

What happens next to ljeoma? Judge Nakamura might decide that lieoma actually can make her own decision. This does not seem to happen very much.



But in that case, Judge Nakamura has to go with whatever ljeoma wants, even if he does not agree with it. So if ljeoma does not want to be sterilized, Judge Nakamura has to ban the sterilization. He has to do this even if he thinks ljeoma would be better off if she did get sterilized.<sup>33</sup>

But let's say that Judge Nakamura thinks lieoma cannot consent. That means the decision is not up to ljeoma anymore. Judge Nakamura will make the decision for her. He can make the decision even if he does not know what lieoma wants. Ijeoma has to go with what Judge Nakamura decides even if she does not like his decision.

## WHAT IS BIRTH CONTROL?

Birth control stops you from getting pregnant. Sterilization is a permanent type of birth control. It lasts for the rest of your life. There are many types of birth control that are not permanent. You can stop them anytime if you change your mind and want to get pregnant. For example, some people use "the pill," which is something you swallow once a day. Other people use an IUD, a type of birth control that a doctor or nurse puts inside of you. An IUD can stay inside your body for several years. Everyone should get to decide if they use birth control or not. And they should get to decide what kind of birth control they want to use.

## **IS STERILIZATION IN IJEOMA'S BEST INTERESTS?**

Judge Nakamura thinks lieoma cannot make the decision on her own. Now the judge makes the decision for ljeoma. Judge Nakamura needs to decide if sterilization is in ljeoma's "best interests," meaning that it is the most helpful option for Ijeoma.<sup>34</sup>

There are usually specific questions Judge Nakamura has to think about when he decides what is best for Ijeoma. Here are some examples of questions he might think about:

- Can Ijeoma get pregnant? Is she having sex?
- Would Ijeoma be a good mother?
- use another kind of birth control instead?

State laws often tell judges how to think about these questions. In some states, the judge can decide which questions are important. That means they can pay attention to some questions but not others. For example, the judge might think that it is not very important to know if Ijeoma might get pregnant. So the judge can decide not to answer that question. Or the judge might allow a sterilization even if there is not a lot of proof that lieoma might get pregnant. When the judge has this much power, it is easier for the judge to decide that someone should be sterilized.

In other states, the judge needs to answer every question and with lots of proof. In these states, it is supposed to be harder for the judge to sterilize someone. But even in these states, some judges do not follow the rules. These judges make it easier to sterilize someone than what the laws allow.

▶ Would it be hard for lieoma if she got pregnant or had a baby?

▶ Is there another way for Ijeoma to not get pregnant? Can she

Here is a real-life example: CW was a young woman who lived in Pennsylvania. Her mother wanted to sterilize her.

In Pennsylvania, the law says you need to prove that sterilization is the only option. You have to show that other types of birth control are not possible for that person. CW had never tried birth control pills. So she did not know if she could take pills.

But the judges said that sterilization was the only possible option for her. They said she might get bad effects from pills, or that she might stop taking them one day. They also said that the pill is not always good for older women, so when CW gets older she might need to switch.

But this is not proof that birth control pills did not work for CW. The judges did not follow the rules, and they made it a lot easier to sterilize CW.35

Some judges also make wrong assumptions about disabled people. Some think disabled people cannot be good parents, just because they are disabled. Some judges say that it would be "tragic" if certain disabled people had babies.<sup>36</sup> Because of these assumptions, judges might think that having children is not in the disabled person's best interest. But many disabled people want to have children. Some need help if they have a baby, like by getting support or services at home. But that does not mean that being a parent would be bad for them.

## **RULES ABOUT THE PROCESS**

Judge Nakamura needs to follow certain rules when he makes his decisions. For example, Ijeoma has to have a lawyer (although she might not be able to choose the lawyer herself). The lawyer should get to tell Judge Nakamura why he should say yes or no to the sterilization. These rules are supposed to make the process fairer for Ijeoma.

In many states, the rules are not good enough.

Here are some examples:

- cases, no one has to tell Ijeoma about it at all.<sup>39</sup>

lieoma usually has to pay for the lawyer, unless she is very poor. And if the guardian is the one asking for the sterilization, lieoma might also need to pay for the guardian's lawyer, too.<sup>41</sup> This can cost a lot of money.

But even when the rules are good, disabled people like lieoma do not have a lot of power in court. And even if there are many rules about the process, ljeoma's sterilization is still a forced sterilization, because ljeoma did not agree to it.

▶ In many states, Judge Nakamura can make a decision even if Ijeoma is not there in person. Some judges say it will not make a difference if the disabled person is there. They say the disabled person probably would not understand what was going on, so it would be fine to decide without them.<sup>37</sup>

Ijeoma might find out that Herman asked for a sterilization only a few days before the judge makes a decision.<sup>38</sup> In some

In many states, lieoma's lawyer can say that lieoma should be sterilized, even if lieoma did not tell the lawyer to say that.<sup>40</sup>

## FORCED STERIL ZATION IS PART O A BIGGER ER

Forced sterilization takes away disabled people's control over their bodies. It takes away their ability to make decisions about getting pregnant or having children. But forced sterilization is just one example of how disabled people do not get to make these decisions. There are many other things stopping them from being able to make these decisions, too. This section is about how forced sterilization works together with those other barriers.

If someone wants to be sterilized. they should get to do that. And if they want to have kids, or if they want to use other kinds of birth control, they should have those options, too.

## Many disabled people do not get to make their own decisions about having children.

But disabled people do not always get these options. Here are some ways that disabled people do not get to make their own decisions about having children:

- Many disabled people have a hard time getting **birth control**. Some doctors who give birth control do not know enough about disabled people. Some assume that disabled people do not understand their bodies. Some assume that they cannot make their own decisions. Some think disabled people do not have sex. This means that many disabled people cannot get birth control, or they cannot get the type of birth control they need.<sup>42</sup>
- Many disabled people do not get sex education. Sex education teaches people about their bodies, using birth control, and having babies. Sometimes a disabled person's relatives or guardians do not want them to learn about these things. Sometimes schools do not teach sex education in a way that includes disabled students. When disabled people do not get sex education, it is harder for them to use birth control and make decisions about getting pregnant.43

## **HEIDI'S STORY**

"Doctors want to give me shots so that I don't get pregnant because they say that I won't remember. But I don't like shots. I want to take the pills. They say, no you won't remember, you won't remember, we have to do this. I didn't like it. I had to tell a friend. She went with me to tell him that I will remember and every day I put my pills in a box. He didn't give me a choice."46

- Most states in the United States allow this.<sup>44</sup>
- Many disabled people do not have good options for disabled people use birth control, deal with periods or it is harder for disabled people to find caregivers.

So forced sterilization is just one way that disabled people are stopped from making decisions about having children.

Many judges think these problems are reasons why a disabled person should be sterilized. They say that a disabled person will have trouble getting other types of birth control. Or they say that the disabled person does not know enough about sex and getting pregnant. Or they say it would be hard for the person to take care of children or the state might take away their children.<sup>45</sup> And when a disabled person faces these problems, that makes the judge think that sterilization is the person's only good option.

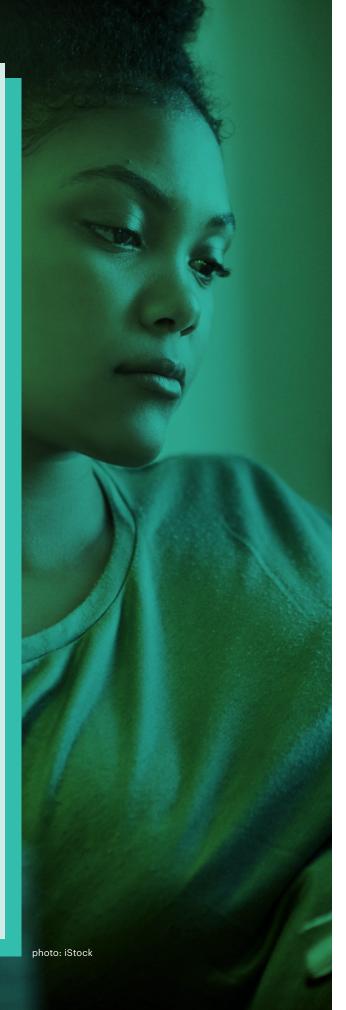
The government sometimes makes things hard for disabled **parents**. For example, the government sometimes takes away a child from their family just because a parent is disabled.

caregiving. Caregivers do important work. They can help pregnancy, and take care of children, if that is what the disabled person wants. But the government does not spend enough money on caregiving. So people who get caregiving have to pay for many of the costs. Many people cannot afford these costs. And because the government does not spend enough money on caregiving, caregivers do not get enough money. That means fewer people want to be caregivers. Then

### **TEMPIE'S STORY**

When Tempie Johnson was just 20 years old, her foster mother went to court to get Tempie sterilized. Tempie said that she wanted to have children. But in court, doctors claimed that sterilization would be in her best interests. They thought Tempie did not act like a mother should.

As proof, they said that Tempie did not pay attention to children when she was younger. They also said that she had an abortion before, meaning that she got pregnant and decided to end it. Her foster mother said that Tempie "went out every night, had boyfriends, came in later than she was supposed to, slept most of the day and refused to take birth control pills." The foster mother also said that Tempie helped clean the house but did not like to cook. The judge decided that this was clear proof that Tempie could not be a good mother. The judge decided to sterilize her.<sup>47</sup>



## **GUARDIANSHIP TAKES AWAY DISABLED PEOPLE'S RIGHT TO MAKE DECISIONS.**

Forced sterilization happens especially to people under guardianship. Guardians can also stop people from making other important decisions. These include decisions about birth control, getting pregnant, and having children.

## Here are some ways this happens:

- Getting an abortion means ending a pregnancy.
- Some people under guardianship do not want to have from getting an abortion, without even asking a judge.
- A guardian can stop someone from seeing their own decision should not be up to the guardian.

## Some people under guardianship want to have children. A

guardian can make them use birth control even if they do not want to use it. The guardian does not need to go to a judge for that, so it is hard for the disabled person to stop the guardian. A guardian can also make them get an abortion even if they do not want to, but the guardian usually needs to ask a judge first.

children, at least not right now. A guardian can stop them from using birth control. The guardian can also stop them

children. And if the guardian gets permission from a judge, the guardian can let the children be taken away. That kind of

## FORCED STERILIZATION SHOWS THE ASSUMPTIONS PEOPLE MAKE ABOUT DISABLED PEOPLE AND GENDER.

Forced sterilization happens more to people who can get pregnant. Many of these people are women. Some people who can get pregnant might have a different gender or no gender, but other people might think they are women.

People make a lot of assumptions about disabled people based on their gender. Many people think that disabled women do not act the way that women should. For example, some assume that a woman should spend a lot of time taking care of children. But they might think that a disabled woman will not do that. They may think that if she has children, she will not take care of them. Many judges have made these assumptions about disabled women when they decided to order a forced sterilization.

Many disabled women are treated like children. People assume that disabled women do not want the same things that nondisabled women want. For example, some people assume that disabled women do not want to have sex. They think that if a disabled woman has sex, that must mean she was forced. And when a disabled woman does want to have sex, many people think that this shows she cannot make good decisions about her body.

People think that disabled women do not or should not have sex. So they think that a disabled woman should not care if she is sterilized. They think that being sterilized does not hurt her in any way. These beliefs make people think that disabled women should not be able to control their bodies.<sup>48</sup> **X** 

## NO ONE SHOULD BE FORCED TO BE STERILIZED IF THEY DO NOT WANT TO BE.

But this is allowed in most states. In 31 states and Washington, D.C., the laws take away disabled people's rights to make this basic decision.

These laws do not just exist in the past. They are here today. They tell disabled people that our rights matter less than other people's rights.

We need to come up with different laws. These laws should allow disabled people to make decisions about important things like whether to be sterilized. Disabled people should get to decide what these laws say.

## WE NEED BIG CHANGES, AND DISABLED PEOPLE CAN LEAD THE WAY.

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## **ENDNOTES**

1. <u>This</u> article says that women with intellectual disabilities get sterilized more and at younger ages.

2. <u>This</u> article says that Black disabled women are especially likely to be sterilized. It says that nearly half (41%) of Black disabled women have been sterilized.

3. <u>Here</u> is Linda's case.

4. <u>This</u> report talks about what happened to Ashley. <u>This</u> article says that many other parents have made their children get "the Ashley treatment." <u>This</u> article talks more about why what happened to Ashley was bad.

5. <u>This</u> article says that all the examples in the bullet points are types of forced sterilization.

6. Here are examples of when judges have said this from <u>Colorado</u> (page 376) and <u>Connecticut</u> (page 530).

7. <u>Here</u> is a report by the United Nations. The United Nations is a group of most of the countries in the world. The report talks about the effects forced sterilization can have on someone (page 12). It says that countries need to get rid of forced sterilization laws because they hurt disabled women and girls. <u>Here</u> is another report that talks about the effects of forced sterilization. It says that forced sterilizations are "an act of violence, a form of social control, and a violation of the right to be free from torture and other cruel, inhuman, or degrading treatment or punishment." This means that they go against basic human rights. 8. The guardian's power to make health care decisions depends on the type of guardianship. Some guardianships are **limited guardianships**. In a limited guardianship, the guardian only has powers over certain parts of a person's life. That might or might not include health care. Other guardianships are called **plenary guardianships**. In these types of guardianships, the guardian has power over all or almost all of the person's life. That usually includes health care.

9. <u>This</u> report talks about what a guardianship involves. <u>This</u> is the Easy Read version of that report. <u>This</u> is a longer report that talks about guardianship. It includes information about when a guardian needs to get permission from a judge (pages 28–29).

10. <u>This</u> is a report by the United Nations. The report talks about forced sterilization laws on page 11. <u>This</u> Easy Read version of the report talks about forced sterilizations on page 12.

11. In four states and one territory, judges say that they cannot order forced sterilizations right now, but they might be able to in the future. These judges say that they need the state to pass a law that allows forced sterilizations first. Judges in these states say that they do not have the power (or jurisdiction) to order forced sterilization without a specific law on it.

12. Forced sterilization started happening before that, in the 1800s. Doctors forced Black women who were slaves to have hysterectomies. They were doing experiments on Black women to find out how to do hysterectomies. The women were awake the whole time. This was a type of torture. But many doctors who did this got a lot of respect. For example, the first person who did it was James Marion Sims. He was the president of the American Medical Association, the main organization of doctors.

## **ENDNOTES CONTINUED**

He is also known as the "Father of Modern Gynecology," meaning that people think he was a very important women's doctor. <u>Here</u> is an article that talks about what happened.

13. <u>This</u> article talks about sterilizations under eugenic laws.

14. <u>Here</u> is an article that talks about how the eugenics movement targeted women of color. <u>Here</u> is another article that focuses on Latinas.

15. <u>Here</u> is the decision in *Buck v. Bell.* 

16. You can read about how the government pressured or forced Native women to be sterilized <u>here</u>. <u>Here</u> and <u>here</u> are articles about sterilization of Latinas. And <u>here</u> is a case where doctors pressured a Black mother into agreeing to have her young disabled daughters sterilized.

17. <u>This</u> is the report that revealed that the women in prisons were sterilized.

18. <u>This</u> article gives examples of judges pressuring people to be sterilized from Tennessee, West Virginia, and Virginia.

19. <u>This</u> article is about women in immigration detention who got sterilized.

20. Generally, judges only decide that a person cannot make their own decision when that person is disabled or when the judge thinks that person is disabled.

21. <u>Here</u> is the Iowa law. The bill that added forced sterilization is <u>here</u> (page 22). <u>Here</u> is the Nevada law (section 159.0806). The bill that added forced sterilization is <u>here</u>.

22. Many judges have said that the current sterilization laws are different from eugenic laws, because they are meant to help disabled people. Here are some examples from <u>Massachusetts</u> (page 559), <u>Michigan</u> (pages 474–475), and <u>New Jersey</u> (pages 246–247).

23. <u>This</u> is an article that talks about what happened to Kirsten. <u>This</u> is Kirsten's court case.

24. <u>This</u> United Nations report said that sterilizations do not stop sexual violence (page 12).

25. Here is an example of a case talking about hysterectomies: Matter of Susan S., No. 7764, 1996 WL 75343, at \*1 (Del. Ch. Feb. 8, 1996).

26. Here are some examples of states that say that the hearing usually has to be private: <u>Colorado</u>, <u>Connecticut</u>, <u>Georgia</u> (section (c)(4)), <u>Hawai'i</u>, <u>Idaho</u>, <u>Maine</u>, and <u>Vermont</u>.

27. We looked at all the court decisions about sterilization that we could find. Almost all of them talk about the sterilization of women and girls. We found only three cases that talk about the sterilization of men or boys. In two of these cases, the judge said that the boy should not be sterilized. The cases are <u>here</u>, <u>here</u>, and <u>here</u>.

28. **These are the 3 states that ban forced sterilization** for children: Connecticut, California, and Vermont. **These are the 17 states that say that it is allowed for children:** Arkansas, Colorado, Delaware, Hawai'i, Indiana, Iowa, Maine, Maryland, Massachusetts, New Hampshire, New York, North Dakota, South Carolina, Utah, Virginia, Washington, and Wyoming.

## **ENDNOTES CONTINUED**

29. These are the states that say that only people under guardianship can be forced to be sterilized: Arkansas, Colorado, Hawai'i, Illinois, Iowa, Kansas, Kentucky, Massachusetts, Michigan, Nebraska, New Hampshire, Pennsylvania, Utah, Virginia, Washington, and Wyoming, as well as Washington, D.C. These states say people can be sterilized even if they are not under guardianship: California, Connecticut, Delaware, Georgia, Idaho, Indiana, Maine, Maryland, New Jersey, New York, North Dakota, Ohio, South Carolina, and Vermont.

30. Here are some examples of states that allow many different people to ask a judge to sterilize someone: <u>California</u>, <u>Idaho</u>, and <u>Utah</u>.

31. Here are some examples of states where there are no laws on forced sterilization, but judges decided they had the power to order sterilizations: <u>New Jersey</u> (page 257), <u>Pennsylvania</u> (page 561), and <u>Washington</u> (page 232–233).

32. Here is an example from <u>Connecticut</u> of how the judge decides if the person can give informed consent. In some states it is harder to show you can give informed consent. For example, in <u>Oregon</u> and <u>California</u>, you need to show that you understand a lot of details about the operation, like the type and effects of the anesthesia (the drug that makes you sleep during the operation). In Oregon and California, it might be easier for the judge to take away the decision from you. But in <u>Massachusetts</u>, a judge said that you do not have to know all the details of the operation to make your own decision (page 568, footnote 8). So in Massachusetts, it might be harder for the judge to say you cannot consent.

33. <u>This</u> case says that if you can consent, a judge has to go with your decision even if the judge disagrees (page 824).

34. In most states, the judge bases the decision based on what is in Ijeoma's "best interests." But in some states, the judge's decision is based on other things, not Ijeoma's best interests. For example, <u>this</u> law from Georgia says a judge can order a sterilization if the disabled person cannot take care of children (section (b)). <u>This</u> law from Arkansas says the judge can order a sterilization if the person cannot take care of themselves.

35. <u>Here</u> is CW's case (page 190). Here is another example from Angela in California: In California, the judges need to be almost certain that someone is going to have sex and might get pregnant. In Angela's case, the judges said that there was almost no proof that Angela will have sex. But the judges decided it did not matter, because there were other reasons to sterilize Angela. The judges made it easier to order a forced sterilization than what the law allows. <u>Here</u> is the California law, and <u>here</u> is Angela's case.

36. <u>Here</u> is one example of where judges have said things like this (page 370).

37. <u>Here</u> is an example where a judge said this (page 1427).

38. For example, in some states the person might find out only 10 days before the hearing, like in <u>Colorado</u> (section (4)), <u>Georgia</u>, (section (c)(4)), and <u>Delaware</u>.

39. For example, <u>this</u> law in Delaware says that no one needs to tell Ijeoma if Herman says it would be "meaningless" to tell her.

40. There are some exceptions. In these states, a lawyer needs to give the judge some reasons why the sterilization should not happen: <u>California</u>, <u>Maine</u> (section (2)), <u>Massachusetts</u> (page 567), and <u>Washington</u> (page 817).

41. For example, here is a law from <u>Arkansas</u> (section (e)(2)), and a case from <u>Illinois</u> (page 425) that say that the guardian might be allowed to use the disabled person's money for costs related to the court process.

42. <u>Here</u> and <u>here</u> are articles saying that some doctors who provide birth control do not treat disabled people well.

43. <u>Here</u> is a study showing that women with intellectual disabilities get less sex education than non-disabled women. It also shows that when disabled women get more sex education, they use birth control more.

44. <u>This</u> report says that two thirds of states allow the government to take away a disabled person's children just because they are disabled (page 16).

45. Here are examples from <u>Idaho</u> (section (3)(d)) and <u>Illinois</u> (page 422). These examples say that the judge should think about how the disabled person would feel if the government took away their children. This would be one reason why sterilization is in the person's best interests.

46. The quote is from this report (page 40).

47. This court case talks about Tempie Johnson's experience.

48. <u>Here</u> is a report that talks about this issue. <u>Here</u> is an example of a judge saying that a disabled woman should be treated like a child (pages 593–594).

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