

## Abortion bans based on fetal conditions

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### Summary

In recent years, anti-abortion activists have attempted to pass bans that prohibit abortion in cases of fetal diagnoses that are expected to cause disabilities. These so-called “disability bans” threaten the reproductive rights of all people by arbitrarily restricting abortion access and limiting a pregnant person’s ability to decide what is best for them and their family. Although supporters of these bans claim to promote the rights of people with disabilities, they, in fact, simply restrict all people’s rights to bodily autonomy and to decide whether to continue a pregnancy, including people with disabilities. These laws, and the anti-abortion activists promoting these bans, do nothing to ensure that families have the resources they need to support all of their children, including those with disabilities; and they do not build support for health care and services that are universally accessible, all of which are key goals of disability rights activists. Disability rights advocates and the reproductive health, rights, and justice communities share core values to ensure all people can maintain their bodily autonomy and make the best decisions for themselves and their families throughout pregnancy; and protecting abortion access is key to achieving those goals.

### The intersection of reproductive justice and disability justice

In the United States, a culture of ableism\* and a lack of attention to disability justice† have at times separated the issues of disability justice from reproductive justice, when in fact these issues are intertwined in many ways. Both reproductive justice and disability justice recognize the intersecting legacies of white supremacy, colonial capitalism, and gendered oppression. They also share values including the right to bodily autonomy, to sexual expression, to have children if desired, to have the resources and support systems necessary to raise children, and to end an unwanted pregnancy.

People with certain disabilities are sometimes characterized in the media and popular culture as asexual and/or unable to be sexually active or become parents. Furthermore, people with disabilities have a history of being sterilized without their consent and are often discouraged from having children.<sup>1</sup> Additionally, when a fetal diagnosis is made and expected to result in serious disability, the assumption is often that the family will want to end the pregnancy. In reality, it is estimated that fewer than four percent of abortions are performed for fetal indications.<sup>2,3</sup>

Every person has the right to be supported in their decision about whether to become pregnant and how to manage their pregnancy. It is critical that those working to protect and expand access to abortion and those working to protect and expand the rights of people who are disabled collaborate to ensure everyone can exercise their right to a safe, healthy, and pleasurable sexual and reproductive life. A recent joint statement by the Committee on the Rights of Persons with Disabilities (CRPD) and the Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW) affirms that “access to safe and legal abortion, as well as related services and information, are essential aspects of women’s reproductive health and a prerequisite for safeguarding their human rights to life, health, equality before the law and equal protection of the law, non-discrimination, information, privacy, bodily integrity, and freedom from torture and ill treatment.”<sup>4</sup> The statement goes on to declare that “states should adopt effective measures to enable women, including women with disabilities, to make autonomous decisions about their sexual and reproductive health, and should ensure that women have access to evidence-based and unbiased information in this regard.”<sup>5,4</sup>

### Prenatal screening and testing

So-called “disability bans” aim to limit access to abortion care based on the identification of fetal conditions prior to delivery. These conditions can be identified through several methods of prenatal screening and testing.<sup>5</sup> Prenatal screening is designed to identify increased risks of conditions but cannot definitively diagnose conditions, whereas prenatal testing is used to diagnose conditions present in the fetus.

- Carrier screening refers to the screening of the pregnant person and their partner/biological parents for genes that are associated with certain genetic conditions. Carrier screening is performed using a blood test before or during pregnancy.
- The fetus can be screened for certain conditions starting in the first trimester of pregnancy.
  - » Traditional screening in the first 12–13 weeks of pregnancy consists of an ultrasound and a test of the pregnant person’s blood. The ultrasound is used to identify increased fluid or thickening at the back of the fetal neck. The blood sample is used to identify two substances that are produced by the placenta and thus found in the blood of all pregnant people. Together, these screening procedures can be used to

\* Ableism is a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be ‘fixed’ in one form or the other. Leah Smith, Center for Disability Rights<sup>14</sup>

† The term disability justice was coined out of conversations between disabled queer women of color activists in 2005, including Patty Berne of Sins Invalid (and Mia Mingus & Stacy Milbern, who eventually united with Leroy Moore, Eli Clare, and Sebastian Margaret) seeking to challenge radical and progressive movements to more fully address ableism. Disability justice recognizes the intersecting legacies of white supremacy, colonial capitalism, gendered oppression and ableism in understanding how people’s bodies and minds are labelled ‘deviant’, ‘unproductive’, ‘disposable’ and/or ‘invalid’. For more information, please see: <https://www.letserasethestigma.com/disability-justice><sup>15</sup>

‡ 3 Ibis Reproductive Health would like to note that while this language is not gender-inclusive, we uphold these values for all people, regardless of gender.



identify an increased risk of a chromosomal condition called trisomy, which is characterized by the presence of an extra chromosome. Forms of trisomy include trisomy 21 (Down syndrome), trisomy 18 (Edwards syndrome), and trisomy 13 (Patau syndrome). These screening procedures cannot provide certainty that a fetus has trisomy.

- » Another option for early screening is cell-free fetal DNA screening, also called non-invasive pregnancy screening, which can be done starting at ten weeks after the last menstrual period. This procedure uses fetal cells that are present in the pregnant person's blood to identify an increased risk of conditions associated with an unexpected number of chromosomes. While this screening procedure is more effective than traditional first-trimester screening at identifying fetuses that have these conditions, many pregnant people do not have insurance coverage for this procedure, which can cost several hundred dollars if paid out-of-pocket.
- Second-trimester screening takes place between 15 and 22 weeks and consists of a test of the pregnant person's blood. This screening procedure can identify an increased risk of trisomy 18 and 21 and neural tube defects, but again, it cannot diagnose these conditions. In order to obtain a diagnosis, prenatal testing using amniocentesis or chorionic villus sampling is necessary. These are invasive tests that are performed during the second trimester and involve taking samples from the amniotic fluid or placenta.
- Finally, the full fetal survey, performed at 18–20 weeks of gestation, can identify major anatomical conditions. It is important to note that some conditions are identified only at the time of the full fetal survey. If at this point, pregnant individuals decide to end their pregnancy, they may have difficulty accessing abortion services. In addition to barriers such as cost and logistical difficulties (read more about these barriers on the fact sheet 'Who needs abortion later in pregnancy in the United States, and why?', from the [Later Abortion Initiative](#)), the declining number of abortion providers nationwide means that there are very limited facilities or no services offered after 19 weeks gestation in many states.<sup>6</sup> Thus, these individuals may face additional costs and logistical barriers due to the need to travel out of state to obtain these services.

### Current laws

Since 2013, and as of 2019, legislatures in 20 states have proposed various abortion restrictions in cases of fetal diagnoses.<sup>7</sup> In 2013, the first of these so-called “disability bans” was passed in North Dakota in 2013 (HB 1305), banning abortion in cases of “genetic abnormality”, even in cases where the fetus was expected to die before or soon after birth.<sup>7</sup> This ban is currently in effect. Ohio (HB 214), passed a ban in 2017 that prohibits anyone from performing, inducing, or attempting to perform or induce an abortion on a pregnant person who is seeking the abortion because the fetus has or may have Down syndrome.<sup>7</sup> In 2019 alone, Missouri (HB 126) and Utah (HB 166) have signed bills into law that prohibit abortion if the pregnant person's sole reason for seeking the abortion is because the fetus has or may have Down syndrome.<sup>7</sup> Arkansas

signed into law a bill (HB 1453) that requires informed consent for abortion to include perinatal palliative care information for patients carrying a fetus with a life-threatening diagnosis. A physician who fails to provide the perinatal palliative care information would have their medical license revoked.<sup>7</sup> In addition, a law in Arizona requires that for abortions being sought for non-lethal fetal diagnoses, counseling be provided on outcomes of people living with the condition with which the fetus has been diagnosed.<sup>8</sup>

### Frequently asked questions

#### *Don't so-called “disability bans” protect people with disabilities from discrimination and maintain disability diversity?*

No. These laws do not improve access to health care, education, or job opportunities, or address discrimination faced by people with disabilities. Instead, they endanger the rights of pregnant people, including those with disabilities, and their families to decide for themselves whether they would like to continue with their pregnancy.

Conversations on disability bans need to include those with disabilities who may be the subject of these bans. Some of these groups may not support abortion rights. This can make the discussion around disability bans tough; however, we can protect and promote the rights of all pregnant people only if we are willing to center their bodily autonomy and ability to make decisions about their lives.

#### *Are abortions for fetal conditions performed “later” in pregnancy?*

It depends. Some fetal conditions, such as trisomy 13, 18, and 21, may be detected using a blood test from the pregnant person as early as ten weeks after the last menstrual period—though these tests are screening tests that require additional diagnostic testing for confirmation. Fetal conditions may also be detected at the time of the full fetal survey, which is typically performed at weeks 18–20 of gestation.

Pregnant people may need some time to arrive at a decision about continuing their pregnancy, since concerns raised by fetal diagnoses may lead to further testing and/or consultations with a range of experts before making a final diagnosis. Fetuses with certain diagnoses often have lower chances of survival than those without these indications at the same gestational age, and while these fetuses may survive labor, some will die shortly after birth. Denying a wanted abortion in these cases may simply delay the inevitable and extend the suffering of the family involved. For those choosing to continue with their pregnancy, comfort measures are offered for those born prior to 22 completed weeks of gestation because of the low chance of survival and high risk of long-term significant impairment among those who do survive (see fact sheet on [The Science of Viability](#)). Literature on the decision-making around the care of periviable<sup>§</sup> infants, much like the discussion on abortion, stresses on the importance of these decisions being individualized and consonant with the wishes of the pregnant person/“parents”.<sup>9,10,11</sup>

§ The American College of Obstetricians and Gynecologists (ACOG) defines periviable birth as delivery occurring from 20 0/7 weeks to 25 6/7 weeks of gestation. It is used to refer to newborns delivered near the limit of viability whose outcomes range from certain or near-certain death to likely survival with a high likelihood of serious morbidities.



Fewer than four percent of abortions are performed for fetal indications. There are several factors that impact why and when people in the United States seek abortion later (i.e., after the first trimester) in pregnancy. Abortion methods are safe and effective throughout pregnancy, and the safety of these procedures has recently been summarized in a report from the National Academies of Sciences, Engineering, and Medicine.<sup>12</sup>

### *Will these bans affect the doctor-patient relationship?*

Making a decision to continue or end a pregnancy can be a complex medical and personal decision that is best left to the patient and treating physician. Politicians are not medical experts, and abortion restrictions infringe on the doctor-patient relationship. The so-called “disability bans” may harm the doctor-patient relationship further by dissuading pregnant people from sharing information with their doctors and not seek medical counseling. For example, in North Dakota, where physicians can be fined and/or imprisoned if they perform an abortion on a pregnant person with the knowledge that the abortion is since the fetus has or may have a genetic condition, doctors may find it challenging to share full information and/or provide people with complete information on all of their options. Patients who wish to have open and honest conversations with their physicians about their pregnancies may be prevented from doing so, and this may hinder their ability to make well-informed decisions about their pregnancies.

In accordance with the Nairobi Principles on Abortion, Prenatal Testing, and Disability, we should advocate for professional and ethical standards and medical education that ensures that providers are trained on the rights and lived realities of people with disabilities, or are able to refer relevant people who can provide this information in an unbiased manner.<sup>13</sup>

## Resources

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15. Project LETS: <https://www.letserasethestigma.com/disability-justice>

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(617) 349-0040  
[lai@ibisreproductivehealth.org](mailto:lai@ibisreproductivehealth.org)  
[www.ibisreproductivehealth.org](http://www.ibisreproductivehealth.org)

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