



# COUNTRY CONTEXTS

Abortion, Prenatal Testing and Disability



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# Introduction

For a number of years now, and in many contexts, disability and women's rights advocates have been talking together about the sensitive issues of abortion and prenatal testing. Recognizing that these conversations are taking place at national, regional and global levels, CREA convened a Global Dialogue on Abortion, Prenatal Testing and Disability in 2018. Context was key. Abortion policies, practices, issues and challenges change as the country context changes – as do cross-movement conversations at the intersections of these complex issues.

This Dialogue – held in Nairobi, Kenya on 29-31 October 2018 – followed two Global Dialogues CREA had hosted:

- The Global Dialogue on Disability, Sexuality and Rights held in Sri Lanka in February 2017

- The Global Dialogue on Fetal Rights and Women’s Citizenship: Implications of the New Gender Ideology, held in Morocco in November 2017.

Both previous Dialogues had already surfaced points of tension between the disability and reproductive rights/women’s rights movements across contexts, particularly around issues of prenatal testing, and abortion on grounds of fetal impairment.

This Global Dialogue aimed to fill some of the gaps in these complex, often difficult conversations, particularly from cross-movement perspectives. The 26 participants at the Dialogue came from diverse constituencies from 13 countries all over the world and from diverse contexts that can broadly be divided into:

- Contexts where abortion is liberalized (India, the US, the UK)
- Contexts where abortion law is moving towards liberalization (Colombia, Ireland)
- Contexts where abortion is criminalized or highly restricted (Poland, Argentina, and Central America).

Within the wider rubric of disability rights, reproductive justice and women’s rights, participants identified themselves as practitioners, researchers, activists, service providers, and involved in advocacy, law and policy.

The idea was to build on the successes of many such conversations being held around the world. One such success is a joint 2018 CEDAW<sup>1</sup>-CRPD<sup>2</sup> statement<sup>3</sup> that strongly affirms the need for States to guarantee access for women, particularly women with disabilities, to sexual and reproductive health and rights. The statement emphasizes the need for access to safe and legal abortion as well as related services and information as being essential to women's reproductive rights.

# Context is key

As the Center for Reproductive Rights notes, the legal status of access to abortion exists “on a continuum, from severe restrictiveness to relative liberality.”<sup>4</sup>

These were the three contexts discussed at the Global Dialogue:

- **Liberalized:** Countries where abortion is legal and available on a wide range of grounds up to the second trimester.
- **Liberalizing:** Countries where abortion reform has resulted in laws that allow access to abortion on specific, often limited grounds and up to a certain period of gestation.
- 5 • **Restrictive:** Abortion is severely restricted or prohibited.





Liberalized

contexts

# India

*“People who are trying to have a male child see this as a perfect end to their obstetric timeline. Girl children are seen as imperfect, inadequate, secondary. This triggers many different issues and must be taken into account.”*

Suchitra Dalvie, Asia Safe Abortion Partnership

*“Do you value the woman who is pregnant, or do you value the fetus? Unless you resolve that debate – and this is a political debate – you cannot put the debate about abortion at rest.”*

Two pieces of legislation shape how prenatal testing, abortion and disability have played out in the Indian context:

- The Medical Termination of Pregnancy (MTP) Act, 1971, which legalizes abortion for up to 20 weeks gestation.
- The Pre-Conception and Pre-Natal Diagnostics Techniques (PCPNDT) Act, 1994, which regulates technologies used for prenatal testing, and bans their use for the purposes of sex selection.

“Since the 1980s, with the availability and commercial marketing of various tests for prenatal testing, India has emerged as one of the largest markets for these technologies. The medical community has been a willing participant in integrating the use of these tests as part of their clinical practice,” writes Rupsa Mallik, CREA, in a case study on prenatal testing, abortion and disability in India that was prepared for this Global Dialogue.

Under the MTP Act, a woman can seek an abortion after the 20-week limit on several grounds, including grave risk to the physical or mental health of a pregnant woman, where the pregnancy is a result of rape or incest, contraceptive failure, or in cases of fetal anomaly.<sup>5</sup> The case study reveals that an increasing number of abortion requests are being filed in Indian courts – by or on behalf of couples or individuals who are seeking termination on grounds of fetal anomaly.

Over the last decade, there has been a demand to increase the

gestational limit to seek an abortion from 20 to 24 weeks. This demand has garnered support among policymakers, public health organizations and the Federation of Obstetrics & Gynecological Societies of India (FOGSI) who argue that late-term abortions on grounds of fetal anomaly must be permitted.

“Disability stigma is deep-rooted in India,” writes Mallik. “While the disability rights movement has contributed significantly to changing this perception, the primary approach to disability still remains an idea that it should and can be *prevented*, and therefore lies the justification for uncritical provision of prenatal testing.”

Although the MTP Act and the PCPNDT Act (which was primarily drafted to prevent sex selection and address the skewed sex ratio in India) are meant to address two different issues, they are often conflated. “Over the past three decades, widespread public perception is that the ‘liberal’ abortion regime fuels sex selection,” writes Mallik. “Compared to the centrality of the sex selection question with regard to abortion legal reform, there has been minimal attention paid to the issue of disability selection by the women’s rights movement and other stakeholders, including those within the disability movement.”

# History

In the 1980s, when gender and sex selection were major bioethics<sup>6</sup> issues, there was a raging public debate on issues of population control, contraception, and abortion.

Sex selection was culturally advertised as desirable; bioethicist Amar Jesani recalls hoardings that proclaimed that by spending a small amount of money on the abortion of a female fetus today, one would save hundreds of thousands later on (referring to the Indian dowry system, in which the bride's family is expected to pay a large sum of money when she is married.)

Liberal economists argued that the fewer the number of women in society, the better they would be treated, while activists argued that this would actually lead to greater violence against women.

Activists then privileged gender justice over other issues, including disability-based discrimination. Western feminists and human rights organizations that advocate for abortion rights critiqued the PCPNDT and the conditionality it enforces with regard to information women can obtain during their pregnancy e.g. the non-disclosure of the sex of the fetus.

For Indian feminists this was less of an issue. While many were supportive of a woman's right to access abortions, they

were equally invested in addressing gender-based sex selection and girl child discrimination and felt that a law like PCPNDT could curb the malpractice in the private sector where sex determination tests were being provided.

Two invasive and high-risk procedures to determine sex (chorionic villus biopsy<sup>7</sup> and amniocentesis<sup>8</sup>) were in use then.<sup>9</sup> Both the medical establishment and society at large considered it acceptable for women to undergo these high-risk procedures, mainly because the ‘risk’ of having a girl child outweighed the risk of health problems or possible abortions caused by these procedures.

“In this context, we knew that when we thought about women’s autonomy, we had to take into consideration that women themselves felt that they were not valued in society, that not having a girl child reduced the risk of family violence against them,” said Jesani. “We came to the conclusion that we needed to campaign for restriction – and this restriction (PCPNDT) was primarily to ban the disclosure of the sex of the fetus by [doctors and laboratories].”

Despite the existence of the PCPNDT Act, son preference continues to adversely affect India’s sex ratio. Son preference contributes to a wide range of practices that enable sex selection that the PCPNDT Act alone cannot address.

Making a distinction between sex selection and sex determination in India, Dalvie pointed out that the former continues

even after birth, in the form of gender-based discrimination. “Girl children are either abandoned, or receive inadequate nutrition and access to healthcare, including immunization,” she added.

The Medical Termination of Pregnancy Act came out of the recognition that high maternal mortality rates in India were partly due to unsafe abortions. A government committee drafted the MTP Act to serve as an exception to Section 312 of the Indian Penal Code that criminalizes “causing miscarriage” to ensure doctors could, on specific grounds and within a specific period of gestation, provide abortions. An elaborate regulatory framework was also created that included registration of facilities and practitioners where abortions can be performed. These needed to be registered by designated authorities.

The MTP Act includes a broad range of grounds including life and health exceptions, and failure of contraception, all of which providers can and have interpreted liberally to ensure access to abortions for women. However, the act is provider-centric, and provider permission is needed for the woman to obtain an abortion. If a provider wants to deny it, they can use their subjective bias to rule out the various grounds that a woman can use to seek an abortion. Since abortion access is contingent on provider permission (one provider for the first trimester and two providers for the second trimester) this can result in denials.

This law did not emerge from the lens of women’s rights, but



ensured that doctors were legally protected if they performed abortions for the sake of a woman's health. "If I as a gynecologist want to interpret it to the broadest possible extent, I can actually provide access to abortion for everyone," said Dalvie. "But if I'm someone who does not want to do that I can create any number of barriers because it doesn't give any protections to the woman in that case."

## Existing and emerging issues

At one time, the only way to test for pregnancy was to inject a woman's urine into a frog or rabbit, wait until this acted on the animal's ovaries, then dissect the animal to see whether the pregnancy hormone was present in the urine.

Now, it is possible to buy a simple home pregnancy test. "Technology has moved from a very labor-intensive, invasive, expensive and complicated process to what we do now," said Dalvie. "I don't think it is difficult to imagine that the kind of prenatal sex determination or diagnostics we are able to offer now will soon be available to people in their own homes."

The following issues were discussed in this context:

**No Dialogue:** While the campaign to curb sex selection has been a broad-based effort that includes the government, the campaign for access to safe abortion has had much less political and civil society attention and support. It has mostly been public health organizations advocating for it, and it is not as much of a movement-based issue as sex selection.

There has been very little dialogue between these two constituencies, and a lack of trust between them. While campaigners against sex selection feel that those advocating for safe abortion have not done enough to address sex selection, those who advocate for safe abortion feel that anti-sex selection

campaigners have contributed to the conflation between the two issues, thereby impacting women's access to safe abortion.

Another space where dialogue is lacking is between the feminist movement and gynecologists. The former is strongly critical of the latter on a number of issues, such as the reliance on unnecessary hysterectomies and Caesarean sections, and the mistreatment of women in the labor room. The lack of dialogue between feminists and gynecologists alienates the latter and may have adverse consequences for the campaign to increase access to safe abortion.

**Conflation of issues:** In the Indian context, the use of the phrase 'sex selective abortion' is being discouraged by activists who want more access to abortion, in order to delink gender-biased sex selection from abortion. This is especially since sex selection can also be postnatal by taking the form of gender-based discrimination against girl children. They argue that constantly linking sex selection to abortion is increasing the stigma around abortion, which is already stigmatized.

This has also affected abortion clinics, and harmed access to abortions, especially second trimester abortions. Implementing authorities for the PCPNDT Act often target abortion providers – through raids and decoy operations – and this has had a chilling effect on abortion provision. Second trimester abortions are particularly targeted because that is when ultrasound can help detect the sex of the fetus; there is a

widespread belief that all second trimester abortions are sex selective abortions.

**Surrogacy bill:** In January 2018, the lower house of Parliament passed a bill banning commercial surrogacy in India. Under this bill, surrogacy is available only to couples who have been legally married for at least five years and are resident Indian citizens. Those who already have children are excluded from the ambit of the bill, unless they have children who live with disabilities, or with a life-threatening, incurable disorder. The bill is pending before the upper house of Parliament.

**Privatized health care:** In India, the private sector – which dominates health care – is relatively unregulated. Medical professionals, who often operate like entrepreneurs, resist regulation. In vitro fertilization (IVF) and fertility have become booming businesses in the ob-gyn community in India. As part of the implementation of the PCPNDT Act, scrutiny has been mainly on sex determination using ultrasound. But there is a larger continuum of Assisted Reproductive Technology (ART) and IVF where sex selection can also take place – this remains less scrutinized even though it has potential for both sex and disability selection.

**Issues with the medical community:** Under the law, it is not the abortion itself that is illegal, but the process of sex determination. Even those who do not terminate their pregnancy after going through this process have done

something illegal. The medical community has gotten divided on the issue – gynecologists are blaming radiologists for carrying out sex determination tests and vice versa.

Very often, women have screening tests (like an ultrasound) done by radiologists who give them no information. If they are shown to have a high chance of having fetal anomaly, they would have to do a fairly invasive diagnostic test (such as CVS and amniocentesis) before they can take a decision. If they are unwilling to do that then the screening is totally unnecessary. (Certain screening tests, including an ultrasound and certain blood tests are done in the first trimester, to check for whether the fetus may have Down Syndrome or heart defects. CVS is also done in the first trimester. Second trimester tests include maternal blood screening, amniocentesis, ultrasound, and glucose screening.)<sup>10</sup>

Medical providers have a monopoly over the provision of technology; if they are regulated they will try to reduce access to it. In the market economy it is in the doctor's interest to play on women's anxieties so that the technology they have invested in gets used. Women are given what is called genetic counseling<sup>11</sup> in order to induce them to have more abortions.

**Culture:** The public conversation around sex determination revolves around ideas like 'If you don't have daughters, where will you get brides?' This resonates more deeply with people's beliefs than the idea of abortion as a right. In a context where motherhood is seen as sacred, and premarital sex is

stigmatized, abortion as a right does not resonate – and is stigmatized.

**Genetic technology:** Genetic technology is opening up in a big way for antenatal treatment – with the new, inexpensive and simple gene editing technology<sup>12</sup> that is emerging. The Indian government is commissioning more research to see what clinical applications this could have. This reinforces the idea that it is desirable to abort a fetus that is showing impairments.

**The law:** Indian law allows termination of pregnancy up to 20 weeks, but there are many diagnostic tests, particularly ultrasound for pathologies related to the heart, spine or brain that cannot be diagnosed until 22 or 24 weeks – the point at which a woman is no longer eligible for terminating the pregnancy if she would like to. When these women go to court, decisions are made arbitrarily, depending on the opinion of the judge for that particular case. There is no consistency when it comes to these judgments.

**Privilege and access:** Parts of India that have some of the lowest sex ratios are also some of the wealthiest parts of the country. As restrictions increased, it was obvious that those who could leave the country to have an ultrasound were doing it, and coming back to have the abortion so that there is no paper trail.

In India marginalized women are not even getting access to

the three standard antenatal visits; they are dying of anemia and postpartum hemorrhage. Maternal mortality is among the highest in the world. On the other hand, privileged women have a series of ultrasounds for everything from prenatal testing to sex determination.

**Understandings of technology:** The uses of technology can be complicated and context-dependent, and are not unidimensional. The ultrasound, for example, can be used for both medical reasons (where there are health grounds on which to monitor the pregnancy) and non-medical reasons (in cases of sex selection or contraceptive failure).

There is a problem with narrow understandings of why the use of technology might be necessary, and trying to restrict the use of technology for ‘non-medical’ reasons. In resource-poor settings, for example, an ultrasound can be life-saving at the time of delivery, as it can help ensure safe delivery. This does not fall neatly into the realm of the ‘medical’ use of the ultrasound, but it can help reduce maternal mortality.

## Questions that remain

*In India, is prenatal genetic diagnosis<sup>13</sup> part of the process of IVF?*

*How much work has been done about informing women about the choice not to test? There is a presumption in the medical profession that all testing is good, and that all information is useful.*

*How far do we need to go in prenatal genetic testing? When we invest in this, what are we not investing in as a society?*

*What are the conditions under which it is acceptable to restrict a woman's choice around abortion and how has that played out in the Indian context? Has there been normative value in making social change around the equality of women because of those restrictions? Have these restrictions reinforced privileges, or have they leveled the playing field between privileged versus marginalized women?*

*Are intersex conditions and sex development disorders mentioned in medical literature, and are they considered disabilities?*

*Who pushed the law against sex selective abortion in India? Politically, who was behind this movement – was it the medical profession, the state, or the women's movement?*



*In cases of fatal fetal anomalies, where pregnancies are unlikely to result in live births, or there are deaths after birth – where can the line be drawn on this from a bioethical perspective?*

*Do prenatal tests have no therapeutic value? Human rights advocates have been pushing for prenatal care, should they then not be included under that?*

*The idea of the disabled fetus is problematic, because it relies on the medical model of disability, and has nothing to do with environmental considerations about how disability is constructed. This is the context in which testing occurs and this has a component of attitudinal change in the medical provision, both from the perspectives of users and providers. How does the counselling about this test occur, what does the result mean, how are providers assessing these results? These are not simply technical questions; they are questions of attitude.*

The  
United  
States

*“Disability justice is markedly different from disability rights – it focuses on cross-movement organizing, solidarity, collective access, collective liberation, and centering the voices of the most marginalized.”*

In the US context, there is a huge power disparity between the reproductive rights and disability rights movements. Internal disparities within movements influence which issues are addressed, and which are sidelined.

In the context of sexual and reproductive health and rights (SRHR), the reproductive rights movement is mainstream and commands far more power, funding and resources than the disability rights movement. Within this framework, it is legal organizations that have the most funding, while reproductive justice occupies a much smaller part of the movement. At this moment, there is very little funding for disability justice in the United States.

The issue that gets the most traction in the US is abortion. In some senses, it is a strongly protected right and in many other ways it is a fragile one. Although it is a constitutional right, it is not expressly enumerated in the US Constitution as a right in and of itself, but has been read into it under the fundamental right to privacy. Abortion rights are currently under threat through a well-funded opposition movement that has been mobilizing since *Roe v. Wade*<sup>14</sup> came into existence. A well-coordinated legal machinery has been operating to overturn *Roe v. Wade*. With the appointment of Justice Kavanaugh to the Supreme Court, it is now increasingly close to doing so.

# Disability rights

From the disability rights perspective, this is a unique juncture in the US. Many foundational organizations created by the baby boomer generation, such as the Easter Seals and United Cerebral Palsy have started to collapse and there is a significant leadership vacuum.

The Obama administration, which had five women with disabilities in office, took the opportunity to start conversations on abortion, consent, diversity, and what campus sexual assault means for students with disabilities – conversations that the ‘old boys’ club’ had not been having. In the post-Obama era, there is a pushback on speaking about these issues in disability rights organizations, since organizations know that not working on intersectionality will not impact funding.

This was exemplified after the 2016 election during the Women’s March in Washington D.C. – the disability platform was initially written by 13 people, 12 of whom were white disabled men. They set the policy agenda for disabled women in the US. It mentioned nothing about reproductive healthcare, and claimed that the number one issue facing disabled women was the Convention on the Rights of Persons with Disabilities (CRPD). “We literally had to take back the agenda. We video-taped ourselves actually throwing it in a shredder, watching it shred and throwing it up in the air like confetti. We said thank you, we’re now redoing things,” said Rebecca Cokley.

In order to continue the conversation on reproductive access, activists are building a bigger tent and bringing more parts of the disability community (that have been traditionally left out or isolated) to the table. This is inclusive of people with eating disorders, chronic illnesses, and women with postpartum depression, among many others – constituencies who have not previously seen themselves adequately represented within the disability rights movement.

In this context, the main issues around abortion and where they intersect with disability in the US are:

**Law and Politics:** The Right has sought to undermine the right to abortion by passing state laws that restrict access to late-term abortion. Advocates in the reproductive justice movement have been trying to stop these laws by arguing that fetal impairment exceptions are necessary. Politically, these impairment exceptions are calculated winning strategies to pull people from the center over to more pro-choice positions.

The right-wing is also strategically trying to promote bans that co-opt human rights language around discrimination. They are pushing states to pass laws that prevent access to abortion on specific grounds – what they call race selection, sex selection, and disability selection. While these three have been frequently patched together, in recent years they’ve introduced standalone bills on disability, or genetic anomaly<sup>15</sup> bans. In many cases these bans are specific to Down Syndrome. The anti-abortion movement believes that people will be more

sympathetic to this ban, since Down Syndrome as a condition has social and political acceptance.

“Disability is being used as a wedge issue by conservatives like never before,” said Cokley.

Advocacy around the sexual and reproductive rights of persons with disabilities has also been hijacked by the anti-abortion lobby. For example, *Breitbart News Network*, a far-right American news website, twisted the words from a report on SRHR by the Special Rapporteur on the Rights of Persons with Disabilities to make it sound like she was against abortion. In this context it becomes necessary for disability and SRHR communities to build relationships with each other.

**Cross-movement work:** There is growing awareness within the mainstream reproductive rights movement about not stigmatizing disability, and a desire to reach out to the disability rights movement to build allyship.

However, there are several barriers that prevent this from happening:

**Political calculations:** The reproductive rights movement’s calculation that fetal impairment ground advances access to abortion, and the framing of this issue in ableist language. Pushback from the disability rights movement has reduced this framing in a public way; however, it is still being used behind closed doors and at the legislative level.

**Political moment:** The reproductive rights movement is desperate for allies and funding. There exists a sense of absolute crisis and doom with the possibility that *Roe v. Wade* may be overturned. In this context, the reproductive rights movement is unwilling to let go of strategies that receive pushback from the disability rights movement.

**Internal resistance:** There is internal resistance within the reproductive rights movement to taking on something new.

**Donor-driven agendas:** Agendas are massively donor driven, and one donor has an enormous amount of power to steer priorities. That donor is not willing to reexamine its abortion-on-demand position from a disability rights perspective.

**Disconnect:** There is a huge disconnect between the SRHR and disability communities on how they engage with the medical community.

**Deference:** The SRHR community defers to the medical community; it respects the doctor-patient relationship and does not want laws to interfere with that. In the context of abortion and the right to information around prenatal testing, it has largely taken a neutral stance, and in some cases refused to support any law that comes between doctor and patient.

The disability community is much more open to the medical community being regulated. The medical community exerts a lot of control and power over disabled persons – the ‘medical



model'<sup>16</sup> of disability continues to have enormous influence. There has been a strong movement against this control. However, the relationship between people with disabilities and the medical community is a complex one, since the former relies on the latter for healthcare.

**History:** There is a history of other movements using persons with disabilities as pawns when it works for them, creating deep distrust within the disability community.

**Gaps:** On the disability rights side, there is a lack of organizations and structures that focus on women's rights and SRHR. This is misinterpreted as the community not caring about these issues even though individual activists with powerful voices care deeply about these issues and articulate them. The challenge lies in how to create structures and support people who may not be equipped to directly engage on these issues.

**Faultlines:** Disability is being used as a wedge issue by right-wing forces, not by the disability rights community. One strategy to counter this is to expose the hypocrisy of the right-wing by pointing out how it is appropriating the disability rights discourse to serve anti-choice agendas. The reproductive rights movement tries to do this, but it doesn't work because this movement itself has a history of eugenics. In addition, the reproductive rights movement has not made the effort to build the role of women with disabilities in its own leadership. Neither has it pushed to change policy agendas to address the SRHR needs of women with disabilities. This

creates faultlines between the disability community and the reproductive rights movement – the latter has failed to demonstrate genuine allyship. Bridge organizations are key to building these relationships.

## Existing and emerging issues

*How is the world of assisted reproductive technology related to ableist views?*

This issue has been taken up from a very limited perspective by advocacy organizations in the US – it has mostly been the LGBT community trying to get access to IVF and eliminate restrictions against access based on sexual orientation. This conversation around access more broadly also encompasses lower income people, persons with disabilities, and people of color.

Abortion rights and access is under threat in the US with anti-choice groups making legal efforts to place gestational limits and other reason-based bans on abortion. The reproductive rights movement has to navigate this but is often unable to take on more intersectional approaches and strategies to advance abortion rights. This constraint is so significant that the movement is unable to build conceptual links between abortion rights and disability rights.

*The doctor-patient relationship has traditionally been held sacred by the reproductive rights community in the United States. It is also something the harm reduction model relies heavily on in restricted settings to ensure that doctors can give women information on how to terminate pregnancies. How has the disability community seen this relationship differently? How*

*has it led to violations and mistrust in the past? How do we come to terms with this across both movements?*

One way to bridge this is through the ‘right to know’ movement. Both the abortion rights and disability rights movements have tried to navigate the contentious issue of selective abortion on the grounds of disability by saying that all women have the right to information, provided it is given in an impartial, evidence-based, non-judgmental fashion.

There is a loose, ad hoc coalition of pro-choice feminist women, parents of children with disabilities who are pro-choice, and medical providers who try to think about how to combat ableism within the prenatal testing and abortion contexts.

Bipartisan legislation has been passed around this at the federal level, by an anti-choice senator and a pro-choice senator. The 2008 Prenatally and Postnatally Diagnosed Conditions Awareness Act “requires the federal government to arrange for the collection and dissemination of up-to-date, evidence-based information about the conditions subject to prenatal and early postnatal diagnosis,” writes Katrina Anderson in a case study on prenatal testing, abortion and disability. “In addition, prospective parents would receive information about resources and services available to families raising children with disabilities as well as connections to other parents raising children with a similar disability.”

The problem is that the implementation of this Act is not being

funded because movements are not calling for it to be implemented, given the reproductive rights community's deep hesitation about interfering with the doctor-patient relationship.

*In the UK, women can have an abortion on request upto 24 weeks of pregnancy. After 24 weeks have passed, they can only have abortions in the case of risk to life to the mother, and substantial chance of fetal impairment. Activists and organizations have campaigned to keep the law as it is because they don't want to close down choice after 24 weeks. Is this a good strategy, or should one law on abortion apply to all?*

Late-term abortion is a really challenging question around which even reproductive rights organizations need to clarify their values. In terms of strategy, there is already so much social stigma around late-term abortion, that one way the reproductive rights movement has found to talk about this is on the ground of fetal impairment. Until public perception on this changes, they may not change this strategy.

The anti-abortion lobby wants to invest in genetic anomaly bans on abortion. This is because advances in prenatal testing mean that genetic anomalies can be detected early (in the first trimester of the pregnancy). If genetic anomaly bans get approved in the law, in effect, this also places gestational limits on those seeking abortions.

## Questions that remain

*What precisely allows the conservative opposition to co-opt disability? How are they seen as legitimately speaking for the community?*

*What is the oppositional strategy, and how are people with disabilities directly involved in it?*

# Liberalizing contexts

# Colombia



*“For all movements in Colombia, rights have been won through litigation. This is true for indigenous rights, for black people’s rights, for women’s rights – and for disability rights.”*

Until 2006, Colombia was one of the most restrictive contexts for abortion in the world, with both doctors and women being criminalized. The Church dominated the messaging around abortion and 30 years of attempts by women's rights groups to pass legislative changes had failed.

In 2006, the law changed – after women's rights groups went to international treaty bodies, which noted that the country's abortion ban was a violation of CEDAW (Colombia is a signatory) and came up with recommendations. Women's rights activists used these recommendations as an input to challenge the constitutionality of criminalizing abortion. The Constitutional Court approved abortion on three grounds:

- If continuation of a pregnancy poses a danger to the life or health of the woman
- If life-threatening fetal impairments exist
- If pregnancy is the result of rape, incest, or non-consensual artificial insemination.

While the Court gave Congress the power to expand on the circumstances in which women could access abortion, Congress has not approved a law on this. Bills (and even constitutional reforms) have been submitted or discussed, but none have reached enough votes to become law.

At the same time, the courts have allowed the mothers of women with disabilities to consent to abortion on their behalf.

The first legal abortion in Colombia involved an 11-year-old girl who had been raped by her stepfather.<sup>17</sup>

## The pushback

There have been pushes at the legislative level to restrict abortion via conscientious objection – which involves giving medical providers the right to refuse to provide a medical procedure, or treatment, on the grounds of their ethical or moral objections to it.

Cristina Pardo, a Justice in the Constitutional Court moved to restrict access in the case of a woman who wanted to abort after getting a fetal diagnosis of holoprosencephaly.<sup>18</sup> She argued that prenatal diagnosis was a form of eugenics and violated the rights of persons with disabilities – and proposed that abortion be restricted at 24 weeks. In an October 2018 ruling on this,<sup>19</sup> the Constitutional Court reaffirmed the right to abortion, and left the 2006 ruling untouched, in a significant win for reproductive rights in the country.<sup>20</sup>

## A disability perspective

With this ruling, women's rights groups in the country realized they needed a disability perspective on the issue.

Due to structural problems, many women in liberalizing contexts are denied abortions<sup>21</sup> even when these are legal. These include lack of effective access to goods and services, barriers including illegal denials of the right to abort, poverty, social stigma, armed conflict.

There are then legal claims against the state as a response to these denials. A few cases have been filed. In cases where children are born with disabilities, these lawsuits are being framed as wrongful birth or wrongful life.

This is the danger of legislative advocacy in extremely right-wing contexts. Instead of litigating on abortion grounds, activists and advocates must find a way to implement the legal framework in a way that makes it less ableist.

There's a lot to learn from the way people with psychosocial disabilities have pushed the implementation of the CRPD on the issue of institutionalization.

The hierarchy within the disability rights movement makes it so that questions about psychosocial disability are even more marginalized. This is something that needs to be kept in mind

if activists are going to explore how the mental health ground can be used across movements.

## Mental health ground

Another factor that has contributed to more cross-movement thinking is that many of the cases for abortion are on the grounds of the mental health and well-being of the woman.

“One way to approach the mental health ground for abortion is to think of any undesired pregnancy as having an adverse impact on the mental health of the pregnant woman,” said Parra.

The presence of grounds creates limitations on access to abortion. But as you begin to eliminate grounds, you can restrict access even further. If you have three grounds to access abortion and you eliminate one because you think it affects persons with disabilities, then you would further restrict access to abortion.

Grounds are never interpreted liberally in many contexts. Although it sounds very technical, the ground for “fetal impairment that is incompatible with life” is actually pretty vague. It is incredibly hard to tell in most cases if the pregnancy is going to be carried to full term and, in that case, if the child is going to survive. And if it survives only a couple of

hours (or a day, a week, a month, or a year) is it viable? Because doctors mediate access to abortion, their own understanding of the concepts of ‘incompatibility with life’ and ‘life’ are essential to access abortion. Some doctors believe that intellectual impairments are incompatible with life, understanding life as ‘life with dignity’. Some doctors are very strict on which cases are ‘incompatible with life’, some are not.

The most problematic part of using the mental health ground is when medical certification is required and a diagnosis needs to go on record. This can be challenging because of the stigma associated with mental health.

Another possible concern with the mental health ground could be that subsuming fetal diagnosis into the mental health ground could potentially invisibilize it to the detriment of actual access. This is the opposite of the intent – which is to broaden the understanding of the grounds on which women can request access.

In summary, the fetal impairment ground already has a lot of critics. If women start using the mental health ground to have those abortions, then that ground is also going to be questioned, and this is going to jeopardize access on that ground.

An issue on which both the reproductive rights and disability rights movements can potentially find common ground is the confidentiality of communications between doctor and patient. That is desirable for both movements.

## Existing and emerging issues

*Is there data for whether women accessed abortion on the mental health ground because of Zika?*

Colombia was highly impacted by Zika. Disability rights groups were excluded from debates around it and from media-generated public discourse. Reports do exist of how many pregnant women with Zika had abortions, but it can't be stated that all of these were motivated by Zika or potential fetal consequences.

*What was the scale of the litigation – was it based on individual complaints?*

In Colombia, a constitutional complaint can be filed in the abstract – no woman needs to expose her case in order to challenge the constitutionality of a law. Subsequent litigation was through specific writs on individual human rights violations. The Constitutional Court reviews all of them – several cases of abortion have been part of this. Some additional standards on conscientious objections were developed through subsequent case laws, but the main challenge happened in the abstract.

All constitutional actions (hundreds of thousands of cases), after being decided by lower jurisdictions, are sent to the Constitutional Court where they are reviewed and some (1%

or less) are selected for decision. Review in this case means that interns read the cases and make summaries for clerks and justices to decide which case is being selected to be decided by the Court. The Court has decided many cases on abortion, upholding the initial 2006 decision (that was not on a case, but on an abstract challenge to the law).

*Women can argue (and have argued) that the idea of having a child with a disability affects them in a way that threatens their mental health. How is this implemented in Colombia?*

The standard in Colombia for the health ground is that you only need a certification from a doctor saying that there is an impact on your health. A woman has to ‘convince’ a psychologist or a psychiatrist that this is the case so they can certify the risk to her mental health. This argument is often used when fetal diagnoses are not ‘bad enough’ to affect the fetus’ viability (which would make the abortion legal), but the woman wants an abortion anyway.

Some of the later litigations included mental health professionals as part of this – so psychologists can say that a pregnancy has an impact on the mental health of the woman, without the need for further explanation.



*How comfortable are activists supporting the mental health ground framing proposed in this session (i.e. the strategic use of mental health to access abortion)?*

There are tensions around the ‘strategic’ use of mental health to access abortion. If they feel it trivializes mental health, for instance. Or if they feel it reinforces the ‘need’ of having a ‘medical’ diagnosis in order for a mental illness to be ‘validated’.

Ireland

*“Restricted abortion access had a disproportionate impact on women with disabilities. Massive barriers existed not only in terms of them being able to travel for access to abortion, but broader access to healthcare, including reproductive healthcare.”*

Maria Ní Fhlatharta, legal researcher, policy advisor  
and human rights advocate

A historic referendum in 2018 overturned the ban on abortion in the People's Republic of Ireland. Before the referendum, abortion was highly restricted in Ireland.

## History

Abortion was first banned in Ireland in the Offences Against the Person Act, 1861, which stayed in effect even after Irish independence. In 1983, the Eighth Amendment to the Republic's Constitution was introduced after a referendum. This amendment meant that the life of the fetus and the mother were seen as being equal under law.

In 1992, a 14-year-old rape survivor was prevented from traveling to England to terminate her pregnancy. This came to be known as the X case. At first, an injunction was granted to the Attorney General, who had sought it to prevent the young girl from terminating her pregnancy.

A Supreme Court ruling overturned this injunction, saying that a woman had a right to an abortion if there was “a real and substantial risk” to her life. The young girl was having suicidal thoughts, and the court held that this risk to her life included the credible threat of suicide.

After the X case and the Supreme Court judgment, two amendments were passed that effectively allowed Irish citizens to

travel to another country for a legal abortion, and learn about abortion services in other countries.

In 2010, the European Court of Human Rights ruled that the state had failed to provide clarity on whether abortion was legally available in case the mother's life was at risk. In 2012, Savita Halappanavar died in a hospital in Galway after she was refused an abortion during a miscarriage, due to the presence of a fetal heartbeat. Halappanavar's death led to widespread protests, and in 2013, the Protection of Life During Pregnancy Act was passed, which legalized abortion (for when doctors thought) a woman's life is endangered by the pregnancy.

In 2015, the United Nations Committee on Economic, Social and Cultural Rights recommended a referendum on abortion. In 2016, a United Nations Human Rights Committee report noted that Amanda Mellet was subjected to discrimination and cruel, inhuman or degrading treatment as a result of Ireland's abortion ban. Mellet, whose scans showed fatal fetal anomaly, had to travel to the United Kingdom to terminate the pregnancy and was later awarded compensation by the government.

In 2017, a citizen's assembly was constituted on the issue of abortion. 100 Irish people got pulled out of the country's register of electors to be part of the assembly. Through a massive citizen-led movement, 14,000 submissions went to this assembly. Activists proposed that abortion be permitted on the

following grounds – sexual violence, fetal non-viability, fetal disability, and danger to health/life.

“Most activists in Ireland did not want grounds-based legislation. We wanted free, safe and legal abortion as early as necessary, and as late as possible, without restriction,” said Maria Ní Fhlatharta, who worked in the headquarters of Ireland’s campaign to liberalize its abortion laws.

However, the situation for Irish women had become so unviable that activists realised that even the smallest wins were necessary, especially since strategic litigation was very difficult in the Irish context because of the Eighth Amendment. It was very difficult to convince Irish women to take up cases and even when they did it was very difficult to litigate for the rights of the woman above the rights of the unborn fetus. The Eighth Amendment effectively acted as a roadblock to doing so – the equal right that it granted to the unborn trumped any other rights.

There were a few strategic litigation cases that were taken to the European Court of Human Rights that were tried at an international level – like Amanda Mellet and the A, B and C cases – based on cruel and degrading punishment and the right to health and equality but they couldn’t trump what was in the Constitution. Ultimately these were only really useful in pushing for a referendum – they couldn’t confer any new rights, which is the objective of strategic litigation, but were useful for movement building.

The citizen's assembly rejected the disability ground because they said that was the work of the disability community – they didn't believe in the restriction of abortion, but also didn't want disability to be the ground on which they expanded on it. Ultimately the assembly decided that 12 weeks without restriction was the most humane way to go forward. The assembly voted 64% to 36% in favour of having no restrictions to abortion in early pregnancy.

These conversations were had prior to entering into a referendum. The conservative government used delaying tactics to avoid having to face this, so they held citizen's assemblies and constitutional conventions, which gave activists the time and space to have deeper conversations and refine the law.

The legislation then went to a government committee – because of their own delaying tactic and the conversations that resulted, politicians realized that abortion was already happening in Ireland because women were taking Misoprostol to terminate their pregnancies. This changed their stance from wanting the most restrictive possible law to agreeing to unrestricted abortion for up to 12 weeks of pregnancy.

What got activists a better law was looking at how they could get the best legislation, and not just at how they could get the most abortions for the most number of people. This brought people on their side, and changed hearts and minds.

with disability grounds. This was extremely unpopular, even within our own movement,” said NI Fhlatharta.

In 2018, the referendum was passed overwhelmingly in support of overturning the ban on abortion, effectively replacing the Eighth Amendment. The Health (Regulation of Termination of Pregnancy) Act 2018 was signed by the President of Ireland in December 2018, and passed in both houses of Parliament. It allows abortions to be carried out up to 12 weeks of gestation, and in certain circumstances, either before or within 28 days of birth. These circumstances are:

- A risk to the life or of serious harm to the health of the pregnant woman
- A condition which is likely to lead to the death of the fetus either before or within 28 days of birth.



## Existing and emerging issues

*How does the mental health ground play out in the Irish context?*

In the case known as the X case, the 14-year-old girl who was raped and whose parents took her to the UK to get an abortion was suicidal. The Irish government ordered that she come home because they wanted to extract DNA from the fetus (as evidence to identify the rapist). She became the center of the Supreme Court case that decided that mental health was part of the danger to life. She ultimately miscarried after being at the center of one of the biggest controversies in Ireland of all times.

The year after, the anti-abortion movement in Ireland had a referendum in order to prohibit danger to life/mental health as grounds for abortion. It failed, but successfully gave rise to the rhetoric that women would pretend to be suicidal or have mental health difficulties in order to secure a termination.

Now, a lot more people are starting to recognize that forced birth and forced pregnancy is trauma, and impacts mental health. The movement also must acknowledge that trauma has a role to play in the broader mental health debate that doesn't play into disability.

## Questions that remain

*Since the disability ground was rejected, will abortion not be accessible in cases of diagnoses of fetal impairment that aren't fatal?*

*What role did international human rights law play in liberalizing the regime?*

Restricted

contexts

# Argentina

*“We live in a eugenic society, and the challenge is to tackle this without criminalization.”*

Abortion is criminalized in Argentina except in cases of rape or danger to the health or life of a pregnant woman – even in these cases, access is sometimes very restricted. According to Amnesty International, more than 3,000 people are reported to have died in Argentina as a result of unsafe abortion since 1983.<sup>22</sup>

## Advocacy

The National Campaign for Legal, Safe and Free Abortion presented a bill to increase access to abortion in 2007.

The first draft of the proposed bill included language that allowed for guardians to consent to the procedure in the case of women under guardianship, which was a problem. The substitution of a person's capacity to act is a serious issue in Argentina and in several countries around the world. This affects women with psychosocial and intellectual disabilities in particular, because of the deprivation they face in terms of legal capacity. Article 12 of the Convention on the Rights of Persons with Disabilities has disallowed this practice. The Argentinian bill also included the provision that abortion would be legal (after 14 weeks of gestation) when the fetus presented "severe malformations".

In 2010, the disabled persons organization REDI issued a statement supporting the bill, but also critiquing it on these

two vital issues.

In 2012, the Federal Supreme Court adopted a progressive interpretation of Article 86 of the Penal Code on abortion. Under Article 86, an abortion carried out by a medical doctor with the consent of the pregnant woman is not punishable if it is carried out to avoid danger to the life and health of the woman, given this danger could not have been avoided by any other means. It is also not punishable if a pregnancy is the result of rape or assault of a woman with psychosocial or intellectual disabilities. The 2012 decision said that this applies to all women without regard of their mental health status (or intellectual impairment). In the latter case, the consent of the legal representative was required, but is no longer required to carry out the abortion.

However, in the same year, the government of the City of Buenos Aires approved a restrictive resolution on the procedure women must undergo to have access to legal abortion.<sup>23</sup>

A group of women's rights and disability rights organizations came together to file a complaint against this resolution. This was a good example of collaboration between the two movements. In the decision of the first instance, the judge granted administrative support for women with disabilities to access abortion. However, the local Supreme Court revoked the decision. Currently, the case is being appealed at the Federal Supreme Court.

In 2016, reproductive rights advocates convened a regional meeting in Bogotá, Colombia to address the question of the fetal anomalies ground and access to abortion. It was a meeting where various tensions arose across movements and no common ground was found. Even so, the opportunity to debate these complex topics was unique, rare and invaluable.

In 2017, a new bill was submitted to Congress and public hearings were held. The bill sought to legalize abortion in the first 14 weeks of gestation. After that time period, it proposed that abortion would be legal on three grounds (risk to health and life of woman, rape and fetal anomalies). The disability rights perspective was taken into account regarding legal capacity; as a result of that debate, the language of the bill abandoned the anomalies ground, replacing it with a ground that centered around ‘unviability’. During the public hearings the question of disability rights was presented both from a progressive perspective and also used by conservative groups as an excuse to oppose the bill altogether.

In August 2018, the Senate rejected the bill. The lower house of Parliament had previously passed the bill, which had the backing of 60% of the citizens.<sup>24</sup> There was tremendous pressure from the Catholic and Evangelical churches to reject the bill – Argentina-born Pope Francis is staunchly anti-abortion.



Poland

*“For the feminist movement to be inclusive of women with disabilities, we need to embrace the latter’s right to take their own decisions, including and also beyond access to abortion.”*

Agnieszka Król, sociologist, researcher and activist

On paper, women in Poland can access abortion on three conditions (if the woman's life or health is at risk, if there is severe fetal impairment, or if the pregnancy has resulted from rape or incest). However, in practice, it is among the most restrictive contexts in the world.

Official statistics show that only 1,061 legal abortions were performed in the country in 2017. "There are whole regions in Poland in which you cannot access legal abortion at all," said Kamila Ferenc, Federation for Women and Family Planning and the ASTRA Network in Poland.

Abortion was not always this inaccessible in Poland. It was legalized in 1956, and was widely available both in private clinics and public hospitals. However, in 1993, a new, much stricter law was passed with the support of the Catholic Church that made abortion illegal in all circumstances except the ones listed above.

## Restrictions on access

In recent years, there have been several efforts to make abortion even more inaccessible in Poland.

In September 2015, a civil initiative to introduce a complete ban on abortion was rejected by the lower house of Parliament. In 2016, anti-abortion activists, led by a project called Stop

Abortion (led by the Ordo Iuris Institute, a Catholic foundation), demanded a total ban on all grounds except where the mother's life was in danger. They proposed that abortion be made punishable with a five-year jail term, and all doctors who perform abortion be criminalized.

In response, approximately 100,000 people (most of them women) marched on the streets in nationwide protests against the proposed ban. It was a women's strike at an unprecedented scale. MPs voted to reject the bill by 352 votes to 58.<sup>25</sup>

In March 2018, there was a push to ban abortion in cases of severe or fatal fetal impairment. This effort, too, led to widespread citizen's protests.

Ferenc listed the following ways in which abortion is restricted in practice across Poland:

- The conscience clause (which permits healthcare providers to not provide some services based on religious or moral conscience).
- The medical practice of extending procedures (requiring unnecessary tests and further medical opinions) so that a pregnancy crosses the deadline stipulated by the law within which it can legally be terminated.
- Tests being conducted at later stages of pregnancy (after 12 weeks).
- Pregnant patients not being informed that they have the

right to prenatal testing. This is the case irrespective of their age, medical history or family history.

- Doctors refusing to issue referrals for prenatal testing.
- Doctors lying about results after patients do have prenatal tests.
- Patriarchal and paternalistic attitudes by medical professionals, and the power imbalance between doctor and patient.
- The risk of penalty for the doctor and anyone else who assists a woman in having an abortion.

Ferenc listed a few advocacy strategies that activists are using to counter this lack of access to safe abortion in Poland:

- Using United Nations tools, like submitting shadow reports to treaty bodies.
- The SRHR community decided to twice propose a bill to make legal abortion possible. They have started the process of collecting signatures for this, and are facilitating discussions and campaigns to provide information about the issue.
- Having huge protests to mobilize lots of women, not only in the feminist movement, but also those interested in protecting the right to health services.
- Preparing an amicus curiae to the constitutional tribunal in a pending case on access to abortion.

“The legal steps will take time and are quite difficult, but the activities based around drafting the bill, starting a [public] discussion and going to the streets has led to the increase of support for legal abortion until the 12th week of pregnancy. Now, 69% people are pro-abortion until the 12th week,” said Ferenc. “This is useful for us to show to the authorities that the pro-choice community is growing larger and larger.”

## Cross-movement work

The feminist movement – including the reproductive rights movement – in Poland is getting more and more visibility, but remains underfunded. The collaboration between the feminist movement and the disability rights movement in the country has started recently and has certain positive aspects, but there are two priorities to consider in this context.

The collaboration becomes difficult or even impossible when there is a lack of accessibility. If feminist movements are serious about cooperating with women with disabilities, they have to bear in mind that there are important practical considerations such as the financial costs of covering the accessibility needs of women with disabilities.

The reproductive rights movement is not addressing the needs and experiences of women with disabilities (e.g. ob/gyn accessibility). For example, some anti-choice women with disabilities have this position because they experience resistance towards their motherhood or were forced to abort. Further, women with disabilities are intensely scrutinized when they become mothers. For example, Król interviewed a woman who was visited by the police after she had a baby, simply because she is disabled.

Women with disabilities were part of the huge mobilization that led to the women's strike in 2016 against the proposed

total abortion ban. However, they had to witness ableist speeches and banners from the pro-choice movement. “[In response] in Kraków we issued a leaflet saying we’re a disability rights organisation and we are a part of the pro-choice movement, please revise the language that you are using,” said Król.

People (in the feminist movement) also assumed that women with disabilities would automatically be anti-choice, and there were accessibility concerns for people with hearing and visual impairments. Despite these difficulties, the movements were able to collaborate, and the speeches and agendas of women with disabilities were represented.

“After the women’s strike, however, the government retaliated by cutting off funds for activities related to women’s rights, especially against gender-based violence,” said Król. They then introduced a one-off financial benefit of 1000 euros (called Pro-Life) to women giving birth to severely disabled children, that again complicated relations between the movements. Although both movements agreed that financial support for persons with disabilities is needed, the form of its introduction raised controversy.

In May 2018, persons with disabilities and parents of children with disabilities occupied the Polish parliament for 40 days. The participation of the feminist movement in these protests was completely ignored by the Polish media, noted Król. “We don’t have sufficient state support for disabled people, and it



is usually women providing care and support. This is why the creation of state support is a feminist issue, firstly because women with disabilities rights are part of a feminist agenda, and secondly, because ableism isn't just affecting people with disabilities, but also the [non-disabled] people in their lives, especially in the economic sense through care work that is a feminized sector.”

## Existing and emerging issues

*What was the process behind creating and submitting the shadow letter on Poland to the United Nations Human Rights Committee?*

Organizations for women with disabilities shared existing material, especially research. The Federation for Women and Family Planning coordinated with the Center for Reproductive Rights and used materials by Women Enabled International to put together all of the information in the letter. The letter mentions not only access to reproductive rights services (like abortion, contraception, sex education) but also mentions issues of barriers and discrimination women with disabilities face in accessing SRHR services and rights, including forced sterilization, and access barriers (in terms of infrastructure, accessibility services, transportation, and more).

*What led to the 40-day occupation of Parliament by people with disabilities?*

It was the decision of persons with disabilities and their parents. They decided to occupy Parliament for as long as it took to get a benefit of 120 euros for support towards independent living and rehabilitation. This was not in consultation with the feminist movement at all; the feminist movement organized in an ad hoc manner to be in front of the Parliament in support of the occupation. The occupation was very well covered by the

media, but the media did not cover the feminist movements' support of the occupation.

*When the disability rights movement requested the reproductive rights movement in Poland to revise their language, they were seen as the opposition. How did the movements overcome this and get back on the same table together?*

The disagreement was akin to a moment of shock for the reproductive rights movement. But feminist disability rights activists resisted ableist language even on social media, and amplified their voices – and made it clear that their agenda wasn't as obvious as the reproductive rights movement had assumed. This led to a dialogue between the activists. Since both communities were part of the larger feminist movement, in which people listen to each other, this dialogue was possible.

*What is the nature of the criminalization of abortion, and whom does it impact?*

It is women and whoever helps them have the abortion (doctors, midwives) who are criminalized. The threat of being imprisoned makes doctors refrain from wanting to make the decision to perform abortion, even when they have no moral opposition to abortion.

## Questions that remain

*One strategy that has been effective in Ireland and other restrictive contexts has been to argue that restrictive laws have a disproportionate impact on women and girls with disabilities since there already exist so many barriers to their access to SRHR services. Has this worked in Poland?*

# Central America

*“The outbreak of Zika affected the Central American region greatly; public authorities as well as health ministries encouraged pregnant women with symptoms or diagnoses of Zika to have an abortion.”*

Silvia Quan, International Disability Alliance

Central American countries have the most restrictive legislation relating to abortion in the world.

In El Salvador, even miscarriages are criminalized. In Costa Rica and Guatemala, the only grounds under which abortion is allowed is if the pregnancy poses a risk to the mother's life, and this has to be confirmed by two physicians. In Nicaragua, abortion is prohibited under any grounds.

“Illegal abortions are quite frequent,” said Quan. “There is a double standard because even though the legislation is restrictive, these are very deeply rooted Catholic societies where the fetus is seen as a person with a right to life... but many a times, even in public hospitals when there is a diagnosis of some impairment, women are encouraged to have abortions. The right to life is valued since the conception, but if it is a fetus with an impairment, the message we get is that that's not life, or that's not a human being.”

# Brazil



*“In the legislation that pertained to anencephaly, a few justices said that any compulsory pregnancy could be understood as a threat to mental health. Some of them even framed it as something that could be understood to be torture, which we understood to be very progressive – an understanding of threat to reproductive rights as a gendered form of torture.”*

## Reflecting on Zika: the Brazilian context

Brazil has one of the most restrictive abortion laws in the world, with abortion criminalized in all cases except in cases of rape, if the life of the mother is at risk, and in cases of anencephaly (the absence of a major portion of the brain, skull, and scalp that occurs during embryonic development).

One in every five women in the country below 40 years has had at least one illegal abortion, and almost five million women are forced to have underground abortions every year.<sup>26</sup> Unsafe abortions lead to 250,000 women being hospitalized yearly, and 200 deaths.<sup>27</sup>

Race and class-based inequalities in the country mean that more black and working class women die of unsafe abortion.<sup>28</sup> Human Rights Watch notes that more than 300 criminal cases related to abortion were registered against women by Brazilian courts in 2017. Many of these were reported by medical professionals after women sought post-abortion healthcare.<sup>29</sup>

## Anencephaly exception

The anencephaly exception was legalized only in 2012, after a legal battle that lasted eight years.<sup>30</sup> In 2004, Anis, a bioethics institute, and the National Confederation of Health Workers led a case for a woman with an anencephalic pregnancy who was seeking an abortion. They argued that forcing her to carry the pregnancy to term constituted a human rights violation.

The woman in question had already delivered by the time the case got to the Supreme Court. But in July 2004, an injunction was granted by the then Chief Justice of Brazil allowing women with an anencephalic fetus to obtain early termination of pregnancy, and for medical professionals to do this without needing a court order. However, in October of the same year, the Supreme Court revoked this injunction, forcing many women to carry their pregnancies to term once again.

In 2012, the Brazilian Supreme Court passed an 8-2 vote in favor of making abortion legal in cases of anencephaly.

## Zika and abortion

In 2015, Brazil saw a widespread epidemic of Zika, a fever caused by a mosquito-borne virus of the same name. This caused many cases of microcephaly, a condition where the head circumference is reduced. The government was heavily criticized for not providing adequate information on the prevention and transmission of the virus, instead only advising women to avoid pregnancy.

In 2016, fueled by the Zika-related advocacy they were doing with the federal government of Brazil, Anis and the National Association for Public Defenders filed a judicial constitutional review asking for a range of measures to be taken around the Zika epidemic, including giving women the right to choose to terminate their pregnancy in order to protect their mental health. “We had just one strategy – that we wouldn’t ask for the fetal impairment ground, but argue for the mental health of women who are vulnerable in the global health emergency,” said Rondon.

In 2017, in a separate case, the Socialism and Freedom Party in partnership with Anis challenged the criminalization of abortion more broadly – on any grounds – in the first 12 weeks of pregnancy.

Both cases are currently pending trial.

# List of participants

**Agnieszka Król** (Poland) is a sociologist, researcher, and activist, and member of Strefa Wenus z Milo association advocating for the rights of women with disabilities.

**Alejandra Meglioli** (USA) is the Director of Programs, IPPF/WHO, where she oversees and directs the organization's programs unit.

**Amanda McRae** (USA) is the Director of U.N. Advocacy at Women Enabled International (WEI), which works to advance the rights of women and girls with disabilities worldwide.

**Amar Jesani** (India) is an independent consultant in bioethics and public health, the co-founder of the Forum for Medical Ethics Society and its journal, IJME (Indian Journal of Medical Ethics, [www.ijme.in](http://www.ijme.in)).

**Andrea Parra** (Colombia) is an attorney, legal activist, translator and experiential trainer. She currently is a core trainer with the organization Training for Change.

**Catherine Hyde Townsend** (USA) serves as an independent consultant and advisor on disability inclusion to private donors, UN agencies, and NGOs with a focus on gender and intersectional identities.

**Florence Amadi** (Kenya) is the Senior Technical Advisor, Community Engagement at Ipas. She has over eight years of experience working in diverse country contexts.

**Gabriela Rondon** (Brazil) is a lawyer by training, who works as a researcher and legal consultant at Anis-Institute of Bioethics in Brasilia.

**Geetanjali Misra** (India/USA) is the Co-Founder and Executive Director of CREA, and has worked at activist, grant-making, and policy levels on issues of sexuality, gender and human rights.

**Iñaki Regueiro De Giacomi** (Argentina) is a lawyer and activist who works as the Gender Desk Coordinator of the Access to Justice Office for Children and People with Disabilities, of the Judiciary of the City of Buenos Aires.

**Jaime Todd-Gher** (USA) works as a Legal Advisor with Amnesty International, where she leads a project focusing on the human rights implications of criminalizing sexuality and reproduction.

**Jane Fisher** (UK) is Director of Antenatal Results and Choices (ARC), which provides non-directive information and support to women and couples through prenatal screening and its consequences.

**Jessie Clyde** (USA) oversees IWHC's grantmaking to feminist organizations in Africa, Asia, Latin America, the Middle East, and Eastern Europe working to advance sexual and reproductive health and rights.

**Juan Sebastián Jaime** (Colombia) is the advocacy advisor for treaty monitoring bodies at the Sexual Rights Initiative.

**Kamila Ferenc** (Poland) is a lawyer, a feminist and an activist who works for the Federation for Women and Family Planning and the socially involved law firm Prawo do Prawa where she provides legal advice pro bono.

**Katrina Anderson** (USA) is an activist and human rights lawyer currently working as an independent consultant based in New York City, where she works on building the capacity of movements and NGOs to engage in strategic advocacy related to gender and sexuality.

**Laura Kanushu** (Uganda) is a lawyer and advocate for progressive policy realization and legislative approaches towards social justice for all, and the Founder and current Executive Director of Legal Action for Persons with Disabilities of Uganda (LAPD).

**Maria Ní Fhlatharta** (Ireland) is a legal researcher, policy advisor and human rights advocate who worked most recently in the headquarters of Ireland's campaign to liberalize its abortion laws – Together For Yes.

**Everlyn Milanoi Koiyiet** (Kenya) has over eight years of experience advancing the rights of women and children and currently works with International Federation of the Red



Cross and Red Crescent as the regional gender and diversity officer.

**Myroslava Tataryn** (Canada) serves as Disability Rights Program Officer at Wellspring Philanthropic Fund after spending 15 years working primarily with NGOs improving access to services for persons with disabilities in sub-Saharan Africa, the Middle East, and the Caribbean.

**Rebecca Brown** (USA), Director of Global Advocacy, Center for Reproductive Rights, is a human rights lawyer who leads the Center's advocacy team in building human rights standards and seeking recognition and implementation of reproductive rights at the United Nations and in other intergovernmental processes.

**Rebecca Cokley** (USA) is the Director of the Disability Justice Initiative at the Center for American Progress, and the former Executive Director of the National Council on Disability, an independent agency charged with advising Congress and the White House on issues of national disability public policy.

**Rupsa Mallik** (India) is Director, Programs and Innovation at CREA, where she develops and implements CREA's strategic initiatives and programs in India, in South Asia and at the global level.

**Shamim Salim** (Kenya) is a disabled, lesbian, Muslim feminist and a human rights activist who has been working towards enhancing policies and structures that promote, protect and enhance the full realization of all human rights.

**Silvia Quan** (Guatemala) has been a feminist and disability rights activist for over 20 years who worked for over 10 years in Guatemala's national human rights institution as the head of disability rights.

**Suchitra Dalvie** (India) is a practicing gynecologist and Coordinator, Asia Safe Abortion Partnership which promotes access to comprehensive abortion services and reduces unsafe abortion and its complications.

The following participants made significant contributions with regard to analysis of country contexts:

### India

Rupsa Mallik, Amar Jesani and Suchitra Dalvie

### The United States

Katrina Anderson, Rebecca Cokley and Catherine Townsend

### Colombia

Andrea Parra

### Ireland

Maria Ní Fhlatharta

### Argentina

Inãki Regueiro de Giacomi

### Poland

Kamila Ferenc and Agnieszka Król

### Central America

Silvia Quan

### Brazil

Gabriela Rondon

# Endnotes

- 1 Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW)
- 2 Convention on the Rights of Persons with Disabilities (CRPD)
- 3 [https://tbineternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/t\\_Global/INT\\_CEDAW\\_STA\\_8744\\_E.docx](https://tbineternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/t_Global/INT_CEDAW_STA_8744_E.docx)
- 4 <https://reproductiverights.org/worldabortionlaws>
- 5 Fetal or congenital anomalies are defined by the WHO as “structural or functional anomalies (for example, metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth, or sometimes may only be detected later in infancy.” <https://www.who.int/news-room/fact-sheets/detail/congenital-anomalies>
- 6 Bioethics is a contested and complex term, relating to the study of the ethical implications of developments in the life sciences. “Stem cell research, genetic testing, cloning: progress in the life sciences is giving human beings new power to improve our health and control the development processes of all living species. Concerns about the social, cultural, legal and ethical implications of such progress have led to one of the most significant debates of the past century. The term coined to encompass these various concerns is bioethics,” according to UNESCO. <https://en.unesco.org/partnerships/partnering/bioethics>
- 7 The Mayo Clinic defines chorionic villus biopsy, also known as chorionic villus sampling (CVS) as “a prenatal test in which a sample of chorionic villi is removed from the placenta for testing. The sample can be taken through the cervix (transcervical) or the abdominal wall (transabdominal). Chorionic villus sampling can reveal whether a baby has a chromosomal condition, such as Down syndrome, as well as other genetic conditions, such as cystic fibrosis.” <https://www.mayoclinic.org/tests-procedures/chorionic-villus-sampling/about/pac-20393533>
- 8 Amniocentesis is a test to check if a fetus has a genetic or chromosomal condition, such as Down’s syndrome, Edwards’ syndrome or Patau’s syndrome. According to the NHS, “...it involves removing and testing a small sample of cells from amniotic fluid,” which is the fluid that surrounds the fetus in the uterus. <https://www.nhs.uk/conditions/amniocentesis/>
- 9 In India, ultrasound came into use only in the 1990s.
- 10 <https://www.marchofdimes.org/pregnancy/prenatal-tests.aspx>
- 11 WHO defines genetic counseling as “the process through which knowledge about the genetic aspects of illnesses is shared by trained professionals with those who are at an increased risk or either having a heritable disorder or of passing it on to their unborn offspring.” <https://www.who.int/genomics/professionals/counselling/en/>
- 12 The US National Library of Medicine defines gene editing technology as “a group of technologies that give scientists the ability to change an organism’s DNA. These technologies allow genetic material to be added, removed, or altered at particular locations in the genome.” <https://ghr.nlm.nih.gov/primer/genomicresearch/genomeediting>

- 13 Prenatal genetic diagnosis is a result of prenatal diagnostic tests that determine where a fetus has genetic diseases. While screening tests test the likelihood of this, diagnostic tests are more definitive. <https://www.healthline.com/health/pregnancy/prenatal-testing>
- 14 A 1973 United States Supreme Court decision that recognized the constitutional right to abortion under its right to privacy clause. Parts of *Roe v. Wade* were overturned by a subsequent decision called *Planned Parenthood v. Casey*; however, the essential underlying framing of *Roe v. Wade* is still intact for now.
- 15 A genetic anomaly is an illness caused by changes in a person's DNA.
- 16 The medical model of disability sees disability as a 'problem' located within an individual. <https://www.disabled-world.com/definitions/disability-models.php>
- 17 <http://news.bbc.co.uk/2/hi/americas/5284604.stm>
- 18 Holoprosencephaly is a disorder caused by the failure of the prosencephalon (the embryonic forebrain) to sufficiently divide into the double lobes of the cerebral hemispheres. The result is a single-lobed brain structure and severe skull and facial defects. <https://www.genome.gov/Genetic-Disorders/Holoprosencephaly>
- 19 <http://www.corteconstitucional.gov.co/relatoria/2018/SU096-18.htm>
- 20 <https://iwhc.org/2018/10/colombias-constitutional-court-defends-abortion-rights/>
- 21 <https://www.reuters.com/article/us-abortion-colombialaw/in-colombia-abortion-is-legal-but-denied-to-many-women-advocates-say-idUSKCN0YG1GX>
- 22 <https://www.amnesty.org/en/get-involved/take-action/argentina-decriminalise-abortion/>
- 23 <http://www.redaas.org.ar/archivos-recursos/Informe%20ADC.%20Marzo%202015..pdf>
- 24 <https://www.theguardian.com/world/2018/aug/09argentina-senate-rejects-bill-legalise-abortion>
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- 26 <https://www.opensocietyfoundations.org/voices/qa-woman-who-challenged-brazil-s-abortion-taboo>
- 27 <https://www.theguardian.com/global-development/2018/aug/02/professor-forced-into-hiding-by-death-threats-over-brazil-abortion-hearing>
- 28 <https://www.pri.org/stories/2018-02-14/brazil-could-soon-outlaw-abortion-altogether>
- 29 <https://www.hrw.org/news/2018/07/31/brazil-decriminalize-abortion>
- 30 <https://iwhc.org/2012/04/brazil-supreme-court-makes-abortion-legal-in-cases-of-anencephaly/>



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