



MAPPING THE ADVOCACY LANDSCAPE

Abortion, Prenatal Testing and Disability

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Introduction

For a number of years now, and in many contexts, disability and reproductive 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 Context 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 CEDAW¹-CRPD² statement³ 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.

Advocacy and movement-building

Around the world, the liberalization of abortion is often accomplished by decriminalizing specific grounds, with fetal anomalies often considered the most ‘socially acceptable’ reason. Meanwhile, advances in genetic technologies are presenting new dilemmas for policymakers charged with formulating rights-based standards that ensure the rights of women and persons with disabilities.

At the Global Dialogue, participants discussed how these and other trends impact the current discourse in human rights standard-setting spaces. They also identified the main global advocacy forums where the issues are being debated and surfaced the strategies that SRHR and disability rights advocates are using to advance rights on these deeply complicated issues.

Sexual and reproductive lives of

women and
girls with
disabilities

“For me, every issue is disability – food, climate change, children, LGBTQ rights. This is because disabled people are people and if you are talking about people, you must talk about people with disabilities.”

Laura Kanushu, Uganda

Across sessions on the sexual and reproductive lives of women with disabilities, participants:

- Looked at the ways in which service provision, culture, social movements and advocacy played out in this context
- Identified challenges to defining the shared interests of the SRHR and disability rights movements
- Shared the ways in which they are using their skills, knowledge and positions to bring about change in this discourse and practice.

Here are the main learnings from these sessions. The companion volume, *Country Contexts*, explores the diverse lived experiences of women and girls with disabilities in exercising their sexual rights and reproductive rights, which were also discussed in several sessions at the Dialogue.

Services

“We don’t understand how difficult it is to hear that raising a disabled child would be a struggle not because of social barriers, but because a disabled child is less, because we are less.”

BARRIERS

Attitudinal

- Service providers have the same cultural and religious biases against abortion and disability as the state.
- Service providers make assumptions and reinforce stereotypes around women with disabilities, leading to them undergoing more prenatal testing, being told to have abortions, and being told they shouldn't be having sex or relationships.
- There is an assumption that people with disabilities are always clients or patients, and never service providers.
- Medical professionals are not trained on patriarchy and misogyny.

Access

- Women and girls with disabilities cannot access healthcare in general, which means that access to reproductive healthcare becomes even more limited.
- The lack of information regarding SRHR increases prevailing violence on girls and women with disabilities. This is reflected in services they are not able to access, both public and private. For example, women with disabilities trying to access an obstetric or gynecological clinic encounter medical staff who don't provide them with reasonable accommodations.
- There are physical, communications, informational and financial barriers to accessing SRHR services. These include transportation, accessibility, lack of interpreters, lack of sex education, and more.
- Services are not low cost or free of cost, even though more women with disabilities than non-disabled women are likely to be living in poverty.

Sexual autonomy and sexual violence

- Hospitals assume that pregnancies have resulted from rape as they don't believe in the sexual autonomy of women with disabilities.
- Taboos around the sexual and reproductive rights of women with disabilities mean that professionals don't provide basic services when women with disabilities face sexual violence.

Pregnancy, childbirth, childcare

- There is a huge unmet need for antenatal care for women with disabilities.
- Doctors don't help women with disabilities who want to have children, and even when they do, they recommend unnecessarily invasive procedures like C-sections which may not be required.

Abortion

- In restrictive contexts,⁴ where abortion is criminalized, women with disabilities cannot access healthcare and end up having unsafe abortions.
- In restrictive contexts, even when medical professionals extend support for access to abortion, they rarely include women with disabilities.
- Prenatal testing has been informed by ableism, with a view to helping women abort a potentially disabled fetus, when it should be framed to be much more inclusive, to not only give information to parents, but also help them better prepare for how to support their child regardless of their disabilities.

SOLUTIONS

Hold trainings, workshops, values clarification for service providers.

Ensure adequate funding to support the training of service providers.

Identify pathways to services, particularly abortion services.

Find doctors to champion issues such as access to abortion.

Educate medical students on the importance of access to safe abortion, thus setting up doctors as agents of change.

Position medicine as a secular profession that does not allow the doctor to turn away someone in need of healthcare, including abortion.

Work with pharmacists as distributors of medical abortion to make sure they're providing services in a skillful manner.

Keep in mind needs that women with disabilities may specifically have around medical abortion.

Recognize and prioritize reasonable accommodations needed by women and girls with disabilities.

EXAMPLES

Agnieszka Król spoke about meeting women with disabilities in Poland who encounter problems with accessing sexual and reproductive healthcare. For example, she met one person who was denied medical confirmation about her ability to have a child, even though her family had this information. This continued until she was 35. Another 30-year-old woman with disability decided she wanted to have a child but could not find a single gynecologist who would agree to support her.

Rebecca Cokley said that in the United States, the Center for American Progress had analyzed campus sexual assault programs in over 700 colleges and universities for disability needs. The analysis looked at what language, support and services were provided around disability, whether sign language interpreters were available, and the disability lens, if any, that they brought to their work. They found that there were no best practices in any of these institutions.

Dr Suchitra Dalvie co-founded the Asia Safe Abortion Partnership, that works with 250 medical students currently in India and some in Vietnam and Nepal to sensitize them on issues of gender and rights.

Ableism

“If the main or only thing you’re working on with regard to SRHR and women with disabilities is fetal abnormality, then you’re not working on the rights of women with disabilities.”

BARRIERS

Institutionalization

- Segregation in education (through boarding school and separate schools for children with disabilities) and adult life (through rehabilitation centers) causes alienation and in the case of custodial homes, can be likened to incarceration.
- When women and girls with disabilities are in institutions, their entire lives are regimented, and they don't have autonomy over any aspects of their own lives, including their right to make reproductive health decisions. Both consensual sex and sexual violence occur within institutions.

Sexuality and sex education

- Women with disabilities are seen as hypersexual or asexual.
- Girls and women with disabilities are not given sex education or access to information about sex. The assumption is that they are undesirable.
- Where there is specific sex education for women with specific disabilities, more general sex education is not designed to reach women with intellectual disabilities.

Reproductive ability, childcare, abortion

- Women with disabilities are not given a choice about whether or not they want to have children.
- Women with disabilities are forced to undergo sterilization, or abortion by their families.
- People assume that women with disabilities will not be able to have children. Even when they do have children, people assume they will not be able to care for their children.
- The challenge of unsafe abortion becomes even more difficult for women with disabilities, because of the taboos surrounding their sexuality and reproductive rights.

SOLUTIONS

Recognize that people with disabilities are not a homogenous community.

Occupy spaces (as a queer person, as a disabled person).

Learn from evidence what works to make disability rights organizations more inclusive. For example, the Department for International Development (DFID) has published its learnings about this.

EXAMPLES

Myroslava Tataryn talked about her experience as a researcher on a pediatric disability study, working out of a pediatric hospital run by an international organization in Malawi. The main floor of this hospital, where all the clinics were, was accessible, but the second floor wasn't. The underlying assumption was that people with disabilities would only access the hospital as patients, not as service providers.

Florence Amadi of Ipas shared a framework that her organization uses – VCAT (Values Clarification and Attitude Transformation) – for internal training and with external partners.

Movements

“Nobody is asking us what we need or think. Ableism is the core reason for this – we, as women with disabilities, are not considered experts or even as people whose opinions are worth listening to.”

BARRIERS

SRHR movement

- The SRHR space still uses the medical model of disability and perpetuates ideas of ‘fixing’ people with disabilities.
- The SRHR movement uses dehumanizing language for people with disabilities in their fight for access to abortion.

Disability movement

- The movement still focuses on education, health and employment for people with disabilities, but not on SRHR.
- In order for women with disabilities to be able to organize on taboo and highly contested issues such as sexuality and abortion, they have to be otherwise privileged.
- Being queer is difficult in disability rights spaces – in an already ableist world, anything that increases stigma can be frowned upon.

Cross-movement work

- In the global advocacy space, SRHR advocates are eager to partner with disability rights advocates when they want to either participate in or influence disability-related spaces, but don't include the latter in other conversations.
- While the SRHR movement doesn't focus on disability, the disability rights movement doesn't have the luxury to not engage with the SRHR movement. If disability rights advocates entered SRHR spaces without knowing key terminology and concepts, they would be perceived as non-experts.
- Women with disabilities who may be otherwise marginalized (on the basis of sexual orientation, class, or other factors) may be forced to pick a movement to prioritize.
- Donor-driven organizations can't necessarily choose to work on issues that the donor doesn't support them to work on.
- Programming work often happens in silos, which means that important cross-movement work and conversations fall into the cracks.

SOLUTIONS

Recognize that organizations working with people with disabilities belong on a spectrum, and are not just of one type.

Work across a continuum – in service provision, at the community level, and for policy and advocacy.

Contribute to the evidence base of everything organizations are working on, since there is not enough data on people with disabilities and access to reproductive health services.

Build internal champions to push the work forward.

Think about accessibility and inclusion in general and in health and humanitarian settings.

Recognize that the difference between the medical and social models of disability stands to benefit a much wider constituency than those we perceive and identify as disabled.

Use a trauma-infused lens. Conversations around sexual violence have been flipped to say that all women who have been assaulted or abused have experienced trauma, and this is a component of disability. This trauma can include consequences of physical and mental health, and conditions like eating disorders – these conversations can be had in a framework that is grounded in disability rights.

Hold workshops with different reproductive rights groups to become stronger allies, so that spaces are more comfortable for people with disabilities.

Think of more disability inclusion as being better not just for disabled women, but for all women. It important to do this on the basis that disabled women are equal citizens and need to be viewed as such.

Leverage opportunities. The abortion and disability debate was revived in the global context a year ago, due to actions by the Committee on the Convention on the Rights of Persons with Disabilities (UNCRPD) and the United Nations Human Rights Council (UNHRC). In these moments, the SRHR movement tends to want to work with the disability movement because the latter gives it more legitimacy in these spaces. Such opportunities can be leveraged to push the SRHR movement towards broader inclusion of women and girls with disabilities in their work.

Choose not to work with SRHR organizations who don't push towards more disability inclusion in their work, and partner more with organizations that do.

Reinforce the fact that SRHR and disability are not different universes, but rather share common strategies. Reframe feminist disability rights groups as part of the larger feminist movement, instead of framing reproductive rights and disability rights as being in tension with each other.

Pause before asking disability groups if they are pro-choice or not when they first enter the SRHR space. This strategy recognizes that coming to a particular standpoint needs time and space, and women with disabilities deserve a safe space where they can reflect upon and shape their own standpoint.

Recognize that cross-movement work and alliances requires discomfort, and that all movements have had to do this at some point.

Build allyship – within the disability justice space it is important to center the voices of the most marginalized women with disabilities, and to support SRHR initiatives led by marginalized women. This lays the groundwork for far-reaching alignments and alliances so that different movements can work on their rights collectively, as opposed to a relatively smaller disability rights movement trying to take on the more powerful SRHR movement.

Ask how disability groups not led by women work with women – instead of refusing to work with them.

EXAMPLES

Maria Ní Fhlatharta spoke about the consequences and aftermath of the death of Savita Halappanvar on the abortion debate in Ireland. Halappanvar, a 31-year-old dentist, was miscarrying, but doctors were not allowed to terminate her pregnancy because of the presence of a fetal heartbeat. A constitutional amendment (popularly known as the Eighth Amendment) passed in Ireland in 1983 put the right to life of what it termed the unborn child as being equal to the right to life of the mother, leading to restricted abortion for all women, with a disproportionate impact on women with disabilities.

Halappanvar's death made her the face of the movement for abortion reform in Ireland. A significant aspect of this struggle around the referendum to retain or repeal the Eighth Amendment has been the involvement and framing of people with disabilities in the debate. Disabled women united to have conversations about the complexities of the issue, and an organization called Disabled Women Ireland was founded by disabled women getting together to campaign on the issue.

Advocacy

*“There are barriers every step of the way.
We need to contribute to the evidence base
– there is not enough data on people with
disabilities and access to reproductive services,
forget abortion.”*

BARRIERS

General

- Laws in many contexts favor the medical model of disability.
- Progressive legislation takes too much time to pass.
- Ableism is the core reason why decision-makers don't consult persons with disabilities – not just in the realm of SRHR rights, but rights in general.
- No one is asking persons with disabilities what they need or think, and they are not seen as experts or even as people whose opinions are worth listening to.

Sexuality

- In cases of psychosocial disability, there are challenges in establishing grounds for consent.
- Legal provisions specifically assume that women with disabilities do not and cannot consent to sex. This reinforces the myth that they are asexual, and cannot fulfill gendered roles and expectations.

Legal capacity and decision-making

- In the criminal justice system, if a person with a disability is deemed to be incapable of making their own decisions, decisions are made on their behalf by the state.
- Many women with disabilities are deprived of legal capacity and decision-making powers. Laws around guardianship and legal capacity exist in almost every country in the world. This leads to forced reproductive health procedures, not being consulted about their own bodies, and someone else making decisions for them.
- Regardless of whether they're deprived of legal capacity, women with disabilities may be seen as not being able to make decisions in their own best interests.

SOLUTIONS

Educate more actors in governments, and the fields of abortion and contraceptive care, and ensure they are compliant with the CRPD.

Think not just about practical barriers that people with disabilities face, but also address issues around legal capacity and institutionalization as barriers to SRHR.

EXAMPLES

Laura Kanushu spoke about the absence of sign language interpretation for access to legal aid in Uganda, even though the country has a provision for interpretation and translation of languages other than English. Kanushu also spoke about the pending women's bill in the country, saying that women with disabilities were not included in conversations about it even though it will clearly impact them.

Alejandra Meglioli talked about how in 2015, the International Planned Parenthood Federation member association in Colombia partnered with three organizations working with people with disabilities after a court decision that the country needed to operationalize the Disability Act. The organization trained all the professionals within its ambit, working with people across 27 clinics. This and other advocacy work led to the approval of the law that stopped forced sterilization in Colombia in 2016.

Mapping the

advocacy landscape

“It would be helpful to have a kind of practical checklist for essential issues to be aware of when we think about advocacy strategies. How can we ask for access to abortion, particularly in restrictive settings, without being ableist?”

Gabriela Rondon, Brazil

There are a number of areas of tension on prenatal testing, abortion and disability within human rights standard setting spaces.

As a result of years of litigation and advocacy by women's rights organizations, there exists a consensus between most human rights treaty bodies (committees reviewing implementation of international conventions) on at least some minimum grounds for abortion. *Abortion Worldwide: 20 Years of Reform*, a briefing paper by the Center for Reproductive Rights, provides a comprehensive worldwide overview of this history.⁵

United Nations treaty monitoring bodies have asked states to decriminalize and ensure access to abortion at a minimum on the following three grounds:

- i. When the life or health of the woman is at risk
- ii. In cases of pregnancies resulting from rape or incest
- iii. In cases of "severe fetal abnormality"

Statements

CRPD Statement

While this consensus was being consolidated, there were three disruptive statements from the UNCRPD Committee as part of its concluding observations on the country reports filed by Spain in 2011, Hungary in 2012 and Austria in 2013. All three of these countries have abortion on demand until a certain gestational age, after which abortion is legal on certain grounds, with the fetal “abnormality” ground allowing for a later abortion than the other grounds.

In these statements, the Committee was not decisive or clear about its framing of the issue with regard to its position on the extended gestational limits that national abortion laws include with regard to obtaining an abortion on the ground of fetal anomalies; first, it framed it under the first part of the Convention, which talks about principles and recommendations, and later it framed the issue as one of discrimination. It was not framed under Article 8 of the Convention, which talks about awareness and stereotypes.

In 2016, the CRPD Committee made similar comments as part of its concluding observations to the United Kingdom's report. The Committee once again reiterated its earlier observations and made note of the different time frame for abortions on the ground of fetal anomalies based on fetal prenatal diagnosis.

Around the same time the CRPD Committee also made a submission to the International Covenant on Civil and Political Rights (ICCPR) on the right to life. In this submission, it stated that under the first part of the CRPD (specifically Article 5 which is on equality and non-discrimination, and Article 8, on awareness-raising), prenatal screening or prenatal testing, and abortion laws that allow abortions based on these grounds, are a potential violation of the CRPD.

These divergent views being expressed by the CRPD Committee on grounds related to abortion created some degree of tension between the various standard setting bodies, namely CEDAW and CRPD. It also caused apprehension amongst those advocating for abortion rights (particularly in restrictive settings) that this could inadvertently result in reduced access and/or provide an opening to anti-choice advocates to advocate for the restriction of abortion.

Recognizing this growing tension and the need to clarify on their respective as well as joint position on the issue, the CRPD and CEDAW Committees released a joint statement asking for access to sexual and reproductive rights to all women, including women with disabilities.

While the joint statement went a long way in clarifying some of the emergent issues across various standard setting bodies, there remains an ongoing challenge to ensure a unified approach to how these complex, apparently competing rights issues can be addressed.

Other key statements

The following are some examples that serve to highlight these tensions and contradictions emanating from various UN standard setting bodies.

- General Comment 7 by the Committee on the Rights of the Child (CRC)⁶ states that “[d]iscrimination against girl children is a serious violation of rights, affecting their survival and all areas of their young lives as well as restricting their capacity to contribute positively to society. They may be victims of selective abortion...”

There is a case to be made about a similar framing being used with regard to fetal impairment exceptions and disability-based discrimination.

- The concluding observations on the 7th periodic report of Poland (2016) to the ICCPR⁷ asks for access to prenatal genetic testing in order to determine whether a fetus has “a severe and irreversible fetal impairment or incurable illness that threatens the life of the fetus.”

During the discussions on General Comment 36 (2018) on Article 6 of ICCPR, on the right to life, Yadh Ben Achour, who represents the government of Tunisia at the UNHRC, openly said that while he is in favor of reasonable accommodations and dignity for people with disabilities, if people can avoid having children with disabilities, then they should. “Though it is necessary to help disabled people once they are born, this doesn’t mean that we have to accept to allow a fetus suffering with impairment to live,” said Achour. “We must do everything we can to avoid disabilities.”⁸

- In 2012, the Inter-American Court of Human Rights struck down Costa Rica’s absolute ban on all in vitro fertilization (IVF) practices. This ban had been enforced in 2000.⁹

Ten couples had earlier petitioned the Inter-American Commission on Human Rights, saying that the ban violated several rights, including the right to private and family life, and the right to found a family, and that it violated the principle of non-discrimination as per the American Convention on Human Rights. The Commission asked Costa Rica to end the ban, and when it failed to do so, the matter went to the Inter-American Court of Human Rights.

The Commission and the couples argued that the ban was tantamount to discrimination against women and people with reproductive disabilities, who rely on assisted reproductive techniques. The state said that infertility did not constitute a recognized disease or a disability which required medical treatment. Relying on the CRPD, ratified by

Costa Rica in 2008, the court concluded that infertility is a disability, and ruled that infertile people need access to treatment.

It must be noted that the majority of the court's judgment was centered on the question of the right to life, and that it concluded that the protection of the right to life at the earliest stages of life was a legitimate claim by the state. The Court held that this protection of the right to life was gradual and incremental, and that fetal personhood only took effect upon the implantation of the embryo.

- In 2017, the Center for Reproductive Rights published a briefing paper on the relationship between the reproductive rights and disability rights movements in the US.¹⁰ The paper explores stigma around disability, sexuality and reproduction, the sexual and reproductive rights of women and girls with disabilities, and the fault lines between the two movements. “[I]n the United States, the anti-abortion opposition is actively working to exploit divisions between both the disability rights and reproductive rights movements by proposing legislation that invokes disability rights as a justification for restricting abortion. Although many in both movements recognize these bills as a blatant attempt to co-opt disability rights in order to restrict abortion access, the movements lack a collaborative strategy to respond effectively to these threats,” it notes.

Gaps

Assisted reproduction

In general, human rights bodies have not said a lot about assisted reproduction. In some cases, they have called for the elimination of excessive regulation and in others, there has been support for some form of regulation. The same body has, on the one hand, supported regulation and on the other, called for access to benefit scientific progress. Most bodies have called for access to IVF for women, but very little has been said about prenatal testing.

Grounds for abortion

All of the treaty monitoring bodies (UNHRC, CEDAW, the Child Rights Committee, or CRC, as well as the International Covenant on Economic, Social and Cultural Rights, or ICESCR) have called for the decriminalization of abortion. Several of them have called for it in all circumstances (particularly the CRC, CEDAW and ICESCR). However, the approach of the treaty

bodies when discussing access to abortion has been based on the three grounds mentioned above: the risk to the life/health of the woman, or if the pregnancy has resulted from rape/incest, or in cases of fetal impairment.

More recently, the CRC has eliminated a listing of grounds when talking about access to abortion. CEDAW calls for broader access in some cases, and in others it takes the grounds approach. There are also inconsistencies around the removal of the listing of grounds in terms of access to abortion. It is important to consider what this means in restrictive contexts.

Right to life

It is possible that the UNHRC may take a more progressive approach while formulating a general comment on the right to life. Perhaps they will frame the discussion around specific grounds in a more expansive way than before.

Prenatal rights

All the treaty bodies are clear that human rights do not begin before birth. The African and European human rights systems support the approach that human rights accrue at birth. The American convention, however, is different. It allows for prenatal protection, but calls for a balancing of this with state interest, and legitimate interest in prenatal life with the rights of women.

Right to information

There are significant gaps in the discussion around the right to information, and the benefits to scientific progress in this particular context. There are tensions between this and the protection of women's reproductive rights, and a need for joint work in this area.

Fetal impairment exception

Under human rights standards, the fetus doesn't have personhood. However, the CRPD Committee has decided that allowing an abortion because of stigma around having a disabled child constitutes disability-based discrimination. Anti-choice politicians seized the opportunity to claim that this meant the committee is pro-life, which it is not. This caused reactions from the women's movement, and the CEDAW Committee, because of the implications it had for access to safe and legal abortion. In order to tackle these tensions, the CRPD Committee approached the CEDAW Committee to see if minimum agreements could be reached. The joint statement they issued is a product of this process.

Possibilities

What more can be done by SRHR and disability communities to build on the joint statement and support the formulation of better and more consistent human rights standards?

More safe spaces can be created to have cross-movement dialogues about priorities, common ground, differences, the identification of internal champions, and stepping up by specific movements, even when it is not the primary issue they work on. Frank conversations will help locate strong allies, and facilitate the cross-fertilization of expertise and the understanding of sensitivities.

More investment is needed to forecast in advance when norm-building opportunities are possible. This is a reactive space and perhaps people haven't arrived at their own positions within their own organizations but are forced to come to one quickly because of advocacy moments. In order to create deeper alliances, and better understanding of shared values and priorities, work can be done in advance instead of only in

reaction to advocacy moments. This can also give rise to the creation of resource documents that can be consulted in an advocacy moment.

More cross-organization work can be made possible by organizations working at the intersection between women's rights and disability rights to support the creation of shared resources and lobby funders.

The politics of friendship – being open and trusting, allows room for when organizations misstep, calling each other out in a respectful way, and sometimes working with internal champions even within organizations with whom common ground is otherwise difficult to find. This will allow us to make slow but sure movement-wide changes.

Understanding (for people outside of the disability right space) that people with disabilities are also human rights experts in general (beyond the particular tension around the sexual and reproductive rights of women with disabilities) is key. The joint statement opens the door for other UN treaty bodies to start discussing these difficult issues with the CRPD Committee.

It is critical to ensure that states are upholding their obligations to fulfill the rights of women with disabilities, including sexual and reproductive health and rights. Getting focused exclusively on this issue to the exclusion of the right to health, education and a full range of other human rights could do a disservice to this project in the longer term. Organizations need to put in

place programming that is supportive of the rights of women with disabilities, and sexual and reproductive health and rights more broadly.

Supporting women with disabilities who want to run for places in any treaty body committees is important. Making linkages between what is happening at the international level and translating this vision into national-level programming is also important, as is decoding what the joint statement can mean at the national level, and how it can be made operational.

Discussion

Would prenatal screening or information related to the pregnancy as a possible ground for abortion after a certain time frame be acceptable to the CRPD Committee? Or would the CRPD Committee see this as a framing that would disproportionately impact people with disabilities?

The idea is not to mention prenatal screening, but rather focus on the rights of women and girls with disabilities to abortion – this is what both the CEDAW and CRPD Committees want to move forward with. Both Committees have been very cautious in not mentioning prenatal screening as grounds for abortion, but just re-emphasizing that women and girls with disabilities have the right to access and enjoy the full variety of sexual and reproductive health and rights.

When we are talking about the problem with advocating for access to abortion based on fetal impairments, but at the same time we are fighting against the idea of fetal personhood, what exactly are we tackling? It is a great burden to hold individual women responsible for discrimination when they decide to terminate pregnancies in specific cases.

Discrimination is against persons with disabilities as a whole, and not against a fetus. This is why the views of the CRPD Committee were issued under article 5, on equality and nondiscrimination.

The ground of fetal abnormality is a breach of the CRPD Convention under article 8, because it is based on stereotypes about persons with disabilities. If the ground is eliminated, women may still have abortions based on prenatal diagnosis, but it would not be a breach of the CRPD Convention.

The mental health ground is very important to have on the table, because – particularly in restrictive contexts – this is a ground that could cover situations of fetal impairment. There are multiple ways the mental health ground can be interpreted.

Building intersectional movements

and
advocacy
agendas

“It is essential to create more safe spaces where we can have conversations about values and clarifications across our movements. We can have frank conversations about priorities, about where we have common ground and where we don’t, about where we can step up.”

Jaime Todd-Gher, US

Participants agreed that many or most of them:

- Had the experience of working within a space that they either suspected or knew had a different position on the issues of abortion and disability rights than they personally did.
- Had sometimes felt that they did not align with their movement's position on the issue.
- Had felt themselves falling through the cracks, and engaging in difficult cross-movement conversations.

Conversations

Participants identified the following challenges to defining the two movements' (sexual and reproductive rights and disability rights) shared interests:

Structural issues

- Both programming and funding function in silos, making it challenging to focus on shared interests. The professionalism of advocacy causes silos to be formed on issues as well as within constituencies.
- Because the disability movement is male-dominated, issues of abortion don't come up as a priority.
- Neither of the two movements prioritize women with disabilities.
- There is a lack of funding for disability, including logistical support for people with disabilities to attend dialogues and meetings.
- There is a general lack of physical accessibility and access to information.
- Academic perspectives on these issues are often removed from people's lived experiences.
- Organizations are overstretched, struggling with competing priorities and have limited capacity to work on these issues.
- Overstretched organizations tend to respond only in moments of crisis.

Cross-movement tensions

- There is a power disparity between these movements – and the sexual and reproductive health rights (SRHR) movement is reluctant to yield space to the disability rights movement.
- There are several issues pertaining to the representation of persons with disabilities, particularly women.
 - The exclusion of women with disabilities
 - The exclusion of the ‘inconvenient’ disabled woman
 - Tokenism
- There is a lack of knowledge.
 - An assumption within the women’s rights movement that all persons with disabilities are anti-choice
 - A lack of knowledge of feminism within the disability rights movement
- Movements are fragmented.
 - A lack of inclusive messaging
 - Agendas are often at cross-purposes
 - Movements are often identity-based, and people with multiple marginalizations are asked to “pick a struggle”
- There is disproportionate emphasis within mainstream disability rights movement on access, less on SRHR.

- Movements position themselves in defensive rather than constructive ways.
- Movements are reluctant to remain in discomfort while working out cross-movement tensions.

Culture, beliefs and religion

- At an individual level, it is difficult to challenge one's internal belief system.
- Parents and families play a huge role in the disability rights movement.
- People have a personal reluctance to talk about issues (such as abortion) that make others uncomfortable.
- There is stigma at the socio-cultural level, that manifests as pathologization and medicalization, adversely impacting people with disabilities.

Intersections

There is a conflict between disability rights and abortion rights that is challenging to reconcile; access to safe abortion is fundamental to a person's sexual and reproductive health rights while pre-natal testing and disability-selective abortion laws serve to further stigmatize persons with disabilities. While there is a divide between movements on these issues, both constituencies do not seek to roll back the sexual and reproductive health rights of women and they are united in the principles of autonomy and self-determination.

Yet, the human rights conflicts around abortion and disability rights remain unresolved. The objective of this conversation was not intended to challenge a person's right to choose but to interrogate the ableist paradigms that often guide these discussions. Participants focused on two types of questions as part of their conversation on the issue as a way to bring movements together around these conflicting issues. These were centered around:

- i. The regulation of technologies, and how to resolve tension between movements in this process.
- ii. Guidelines for service providers to make them less ableist in their approaches.

The following is a full list of the concerns that emerged as part of this discussion:

Advocacy

- In contexts where fetal impairment exceptions to abortion laws exist, should activists advocate for or against keeping them?
- How do we tackle grounds of fetal impairment in restricted settings?
- What can advocacy look like in contexts where access to abortion is extremely restricted? What are we protecting, resisting and negotiating with, while not restricting access further?
- How should we advocate around norm development in international standards? What do we want human rights bodies to be saying?
- How do we ensure that we protect the right to terminate any unwanted pregnancy while recognizing that unwantedness may emerge from environments of discrimination?

Ableism, access and service provision

- What are the ableist ways in which fetal impairment exceptions are implemented?
- How can ableism be reduced without reducing access to abortion?
- Can mental health grounds be used to give access to abortion, so that the grounds are not around fetal impairment and unviability?
- What is ableist in the practice as it happens now?
- What are the underlying assumptions and motivating factors around prenatal screening vis a vis ultrasound? There are multiple therapeutic reasons to have an ultrasound, but the fundamental reasons for certain types of screenings come from ableism. Why are some technologies more motivated by ableist conclusions, and others used for more therapeutic reasons?
- What is the most sensitive language through which we can best frame prenatal screening? How do we also ensure this language is effective in the real world in order to support women's choices through screening?
- How do we feel about restricting and regulating new technology in the name of promoting and protecting the rights of persons with disabilities? Does restriction ever work?

- How far do we go with screening, especially genetic screening, especially as the science of interpreting them is still evolving. Who regulates this?

Social movements

- What are the continuing tensions between SRHR and disability rights advocates? How can we resolve them?
- How can we make sure women with disabilities are involved in SRHR advocacy? How do we tackle the ableism within movements that restricts their involvement?
- We know that restricting access to abortion doesn't lead to fewer abortions – what do we, as coalitions, think the best approach is to tackle this?

Frameworks

In a working session, participants identified what would be most helpful for them to think through grounds for abortion after the meeting. This exercise laid the groundwork for the creation of outcomes documents from the convening that can be used in advocacy at the national, regional and global levels.

Cross-movement work

- Shared understandings about practical, incremental strategies that do not harm persons with disabilities in general and women with disabilities in particular, and form the basis for building relationships for a more joint and integrated movement.
- These shared understandings could take the form of do-no-harm principles and strategies born out of a consultative approach, and be encompassing of approaches to allyship and cross-movement work.

- Reframing the discourse of the reproductive rights space should be a priority, with language being the starting point. Critiques from the disability movement about how language is deployed in the reproductive rights space need to be taken on board, and a common language has to be found.
- Beyond language, it is important to unpack what choice and autonomy means for women with disabilities.
- Many successful examples from many country contexts have not been well documented. Amplifying these, and demonstrating what has gone well is something everyone in the room can possibly commit to. This is especially helpful in terms of securing funding to do this work, since donors want to see examples of both individual and institutional success.
- Both parties in the discussion on abortion and disability – the SRHR community and the disability community – have a responsibility to go deep into discussion. There is a moral debate underlying this conversation that has not yet been made explicit, uncovering it involves asking direct, difficult questions such as whether prenatal testing is ableist.
- Promoting access to more information, and mobilizing people to make culture in general less ableist can modify positions.

Access to abortion

- An understanding of what unbiased information (as a right that should be available to all women) looks like in the process of accessing abortion.
- With regard to the full decriminalization of abortion and not having any gestational limits, movements need to come to an understanding of who will regulate what abortions are provided. There is an assumption that abortion will continue to operate within legal frameworks.

Prenatal testing

- The conversation around prenatal testing has to be unpacked in its own right instead of simply being an addendum to the conversation on access to abortion. There needs to be a deeper understanding of the field of testing, involving conversations with people who are not in movement spaces. This would be a pathway to figuring out what questions advocates need to ask.
- If it is necessary to make an intervention regarding prenatal testing, it should center around meaningful autonomy, based on full and informed consent.
- A draft set of principles committing to tackling ableism in prenatal testing, and access to abortion, would be very helpful.

Advocacy

- A practical checklist for advocacy and service provision could be drawn up, in which participants could agree on what to do and/or be aware of when thinking of advocacy strategies.
- Advocacy at the international level:
 - Advocates should closely follow all recommendations on abortion and push back against the specifying of grounds for abortion. If advocates are pushed to mention grounds, these should only be centered around the autonomy of women.
 - Having a clear position about discrimination: Most participants agree that this situation is in violation of the CRPD. If we are forced to answer to this argument in public, this will have an impact on how we move forward, and many consequences for multiple movements. It will affect the disability movement's discussion on euthanasia, and impact many other disability justice issues.

Service provision

- It is important to recognize that there is ableism in the way services are provided.

KEY QUESTIONS

Based on this exercise, participants split into four groups and worked on the following questions:

- A set of questions that SRHR groups can ask themselves to be more disability inclusive
- What unbiased information can look like in prenatal testing and counseling processes
- What to do about abortion grounds in restrictive and highly restrictive contexts
- A set of principles on prenatal testing, abortion and disability¹¹

The outcomes of this group work are listed below.

OUTCOMES

Questions that SRHR groups can ask themselves to be more disability inclusive

This group considered the following key categories as essential to considering whether an SRHR group is inclusive:

Accessibility

Physical, informational, in the built environment, and in the availability of services.

Unbiased information/knowledge

- Does the information include medical and social information and is it grounded in cultural realities?
- How are you disaggregating your information, does it include disability?

Disability culture/knowledge

Breaking down biases and stereotypes, socio-cultural norms, and awareness about disability, and the diversity of the disability community.

- Do you interrogate how you see disability fundamentally, and what assumptions you make about it?

- Does your organization account for the systematic oppression of people with disabilities? For example, do you provide disability trainings for your staff?
- Do you incorporate a disability rights lens in your intersectional analysis?
- How did you develop your disability rights lens? Who is it informed by – medical context, local community?

Representation, participation and consultation

- How have persons with disabilities informed your priorities?
- Have you engaged with communities of persons with disabilities in developing your work?
- Do you have openly disabled staff?
- Do your reports/outputs portray persons with disabilities? How are they represented?
- Who does the disability rights organization you work with represent? Are the disability rights organizations you are working with inclusive? (i.e. on gender, sexuality, race, socio-economic class.)

Inclusion

More broadly, in the branding and image you convey to the world/communications, diversity, language.

- How does your organization include disability in its 'diversity' efforts?
- Are disability issues addressed across all of your programs of work?
- Is the language (i.e. on website, PR issues) that you use informed by the disability community?

Autonomy, legal capacity, choice, right to information

Community partners/key players

Accountability

Note: The group also identified critical next steps on who needs to be consulted further, what they need to complete the process, and how the document could be rolled out and promoted.

What unbiased information can look like in prenatal testing and counseling processes

It is important to develop a clearer idea of what is meant by ‘good information’ to be provided prior to, and throughout the process of prenatal screening so that prenatal testing can be delivered free of ableist biases, as equitably as possible. The context in which this ‘good information’ is located is critical to how this information will be perceived. Information providers must be ready to support a woman following the screening results - regardless of her choice. If the assumption isn’t that she will necessarily want to terminate then things will be done differently.

The group proposed the following next steps:

Reconvene the committee that met as a small group in Nairobi (with additional members) in order to create a document defining ‘what is meant by good clinical information’.

This needs to draw on any existing country-level and WHO guidelines and should cover the following fields of clinical information: diagnosis, imagined treatments, assignment of a key focal person to guide the mother through the screening process. It should outline the social service, and civil society

support networks (community organizations, peer support groups, etc.) that should be mapped out in any given country/ context and shared during the screening process.

Identify a partner to adopt use of the guidelines as a model/ test case.

This could be an organization such as IPPF that works in different countries to improve access to SRH services (including pre-natal screening). This model-pilot based on the guidelines could learn / be inspired by the roll-out of one-stop GBV crisis centers in Delhi. Roll out of the guidelines must include staff training on talking about disability in value-neutral ways and include the provision of psychological support for parent/couple.

Disseminate guidelines widely and promote uptake by other organization (after the successful roll out of step 2 above).

What to do about abortion grounds in restrictive contexts

Principles

- Any strategy and process around this should always significantly include the disability rights movement.
- Anything that is decided in this meeting that people with disabilities don't agree with has no value.
- If in a particular context there is not a lot of leadership of people with disabilities, it does not relieve movements of the responsibility of including people with disabilities.
- SRHR organizations need to promote the feminist leadership of women with disabilities.

Context

This group considered the following question: In the most restrictive contexts, i.e. where abortions are totally illegal or only allowed when there is a risk to the life of the woman (without any consideration about her health), what would be considered a step forward?

- On grounds of “fatal fetal abnormality” or “severe fetal abnormality”: This would never be recognized by the disability rights movement, but we have to recognize that in practice, it is the best grounds for access to abortion because one only needs the diagnosis to have this abortion,

without any other considerations.

- The fetal non-viability ground is – in the abstract – less problematic in terms of disability rights, but this would depend on the conversations one has with the disability rights movement on this.
- In all restrictive contexts, a possible solution would be to broadly implement the health grounds, and even where viability grounds exist, try to avoid these in favor of health grounds. This requires investment in counseling and good information.

A set of principles on prenatal testing, abortion and disability

A discussion at the Global Dialogue gave rise to the Nairobi Principles, a set of 13 Principles that address the complex issues that lie at the intersection of reproductive rights and disability rights.

The Preamble to the Principles affirms that “sexual and reproductive rights, including access to safe abortion, are important priorities for both sexual and reproductive rights advocates and for women and girls with disabilities” and recognizes that “there is no incompatibility between guaranteeing access to safe abortion and protecting disability rights.”

It acknowledges the pivotal role women and girls with disabilities play in “discussions on sexual and reproductive rights, including access to safe abortion, and that their inclusion in conversations that affect them is essential to ensuring both their rights and the rights of all women and all persons with disabilities” – and finally, recognizes the need to bring together reproductive rights and disability rights advocates together to work on these issues.

The Principles can be accessed at:

<https://nairobiprinciples.creaworld.org/principles/>

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The following participants made significant contributions with regard to the discussion and analysis of the sexual and reproductive lives of women and girls with disabilities:

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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://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/1_Global/INT_CEDAW_STA_8744_E.docx
- 4 Contexts in which abortion is severely restricted and prohibited.
- 5 https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/20Years_Reform_Report.pdf
- 6 <https://www.refworld.org/docid/460bc5a62.html>
- 7 <https://www.ohchr.org/en/countries/enacaregion/pages/plindex.aspx>
- 8 https://www.google.com/url?q=https://www.huffingtonpost.com/entry/un-human-rights-committee-stop-equating-life-with_us_5a0323e2e4bob422a3c5ce16&sa=D&ust=1550072929293000&usg=AFQjCNHbe4n6IndkSMomqG_6koqSoTHvyy
- 9 http://www.equalrightstrust.org/ertdocumentbank/ERR1o_sp4.pdf
- 10 <https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/Disability-Briefing-Paper-FINAL.pdf>
- 11 A working group of participants at the convening drafted and refined these principles; they can be found here: <https://nairobiprinciples.creaworld.org/principles/>



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