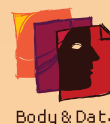


BEYOND ACCESS

*Women and queer persons with disabilities
expressing self and exploring sexuality online*



Beyond access:

Women and queer persons with disabilities expressing self and exploring sexuality online

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ABBREVIATIONS

APC: Association of Progressive Communication

FGD: Focus Group Discussion

ICT: Internet and communication technologies

LGBTIQA+: Lesbian, Gay, Bisexual, Transgender and Queer, Intersex, Agender, Asexual and Ally community

NDWA: Nepal Disabled Women Association

NGO: Non governmental organization

PWD: Persons with disabilities

SRH: Sexual and Reproductive Health

SRHR: Sexual and Reproductive Health and Rights

UN CRPD: United Nations Convention on the Rights of Persons with Disabilities

WWD: Women with disabilities

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Shubha Kayastha

EXECUTIVE SUMMARY

Women and queer people with disabilities face layers of discrimination amidst the Brahminical patriarchy, queerphobia and ableism pervasive in Nepali society. These hinder women and queer people with disabilities from freely exploring and expressing their opinions, and accessing information and services around sexuality. These hurdles exist despite the presence of various legal provisions for their rights. They are subject to constant judgment and ridicule for their choices and desires. People with disabilities (PWD) are expected to behave, express and present themselves based on the parameters set by abled bodies for abled bodies themselves. Under this framework, there are assumptions about what the basic needs of PWDs are, a view that generally excludes aspects of sex and sexuality. Further, the dominant discourse around PWDs looks at them as objects of pity, needing support, and incapable of agency. All this in turn erases their multiple realities and narratives of resistance, and excludes the intersectionality that these bodies carry.

In such a scenario, online spaces have been an escape for women and queer individuals with disabilities to explore and express themselves, while evading some of the restrictions faced offline through surveillance within the family or outside. Facebook is the most common platform used by the participants, with Facebook messenger as the common mode of communication. Women and queer persons with disabilities use online spaces for work, to learn skills, exchange greetings, or entertain themselves. They also curate spaces where they feel comfortable; spaces which they use to express themselves through their opinions, poems or photos; or spaces where they can vent out. They share their sexual lives in small groups of friends and co-workers. They also use the internet to exchange and express sexual pleasure with others and explore dating, even though these activities could be restricted for them offline.

The understanding of the word sexuality ('younikta' in Nepal), is loaded with the concept of decency and indecency, and directly connotes sex. Thus sexual expression is often misunderstood as sharing details of one's personal sexual life, when in reality sexual expression encompasses a much wider spectrum of activities. We saw this dichotomy in the research participants' understanding of the term sexuality, in that only a few perceived their activities as falling under the umbrella of sexual or erotic expression. Yet many of our participants reported sharing photos and content from events and conferences related to sexual and reproductive rights. They saw this as solely part of their activism, boxed away from personal expression. The research participants also reported regularly using the internet for information on beauty, sexuality and sexual health. These examples showed that "sexuality" and expressions of sexuality were understood in a limited way.

Online spaces are also not devoid of challenges and risks. Our study finds that hurdles to using the internet for self expression include: lack of access to devices and skills to navigate digital technologies, expensive data costs, language barriers, and insufficient disability-friendly content, tools and applications. In addition, participants stated that their internet use was also restricted by socio-cultural factors, including overprotection and monitoring of online behavior by families and partners. Similarly, participants also flagged lack of representation in pornography and lack of accessible-format pornography as shortcomings to exploring sexuality.

The research participants consisted of activists with disabilities who shared their understanding of 'good' and 'bad' expressions; some their own conception, some imposed. There was a prevalence of internalized expectations such as the need to always project a "motivational" image for the disability community, and shaping

their own online behavior accordingly; these expectations also limited free and spontaneous expression. The only sexual expressions accepted in general Nepali society are those that fit into heteronormative social norms, such as heterosexual marriage. The sexual expression of women and queer people with disabilities was discouraged offline, and this was mirrored online as well. This policing occurred not just from participants' social circles but also from within the disability rights movement itself. Self-censorship of sexual expression was prevalent, and this was to avoid being judged, ridiculed, being labeled as hypersexual, or to avoid unwanted sexual attention (referred to as 'negative attention' by the participants).

However, many participants affirmed that conversations around sexuality of women and queer persons with disability and acceptance of their sexuality were important issues. There was an assumption that talking about sexuality, pleasure, and consent leads to social disapproval, which in turn prevented consensual, mutually beneficial exploration of pleasure. Even those who indulged in internet content on sexual pleasure avoided sharing it online out of fear of losing credibility as activists.

Women and queer people with disabilities face violence and harassment that is often invasive. They are targeted for their identities as women, as queer individuals, and as persons with disabilities. The participants reported facing harassment that ranged from oversexualized comments to being solicited for sex. Some of the violence took the form of microaggressions, where persons with disabilities were given backhanded compliments expressing admiration for being beautiful or successful despite disability, that they did not "seem disabled". Other aggressions manifested as emotional labor, where women and queer persons with disabilities were constantly asked by abled persons to answer their questions and satisfy their curiosities. Participants also found that having a choice whether or not to reveal their ability status was liberatory, allowing them to explore other aspects of identity. Some even used this choice in a strategic manner to tackle unwanted attention.

Given the nuances of how women and queer persons with disabilities are navigating digital space to express themselves and explore their sexuality, Body & Data has put together this exploratory research 'Beyond access: Women and Queer Persons with Disabilities Expressing Self and Exploring Sexuality Online'. The research study was carried out among women and queer people with disabilities through in-depth interviews and Focus Group Discussions (FGD) to understand their internet use for sexual expression and self-expression.

INTRODUCTION

In Nepal, phase I of the EROTICS South Asia report (2017) research looked at the myriad ways in which online violence against women mirrored offline gender relations.¹ This research explored the use of internet among gender equality and sexual rights advocates in Nepal.

Second Phase of EROTICS South Asia is a continuation of this research, focusing on the experiences of a sample group of people who have been limited to stereotypes in dominant narratives in Nepal and across the globe.

When we began the quantitative research we saw the need to include the experiences of women with disabilities in Nepal. So with our qualitative research, we explored how women and queer persons with disabilities used the internet as a platform to express themselves sexually and to provide readers with a deeper understanding of the challenges and risks associated with their internet usage. This research looks at the complex layers of discrimination and marginalization that lead to women with disabilities being ignored, often even within their broader groups of marginalization ie. women, queer, as well as disabled people.

Why this research?

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines disability as “an evolving concept resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”² In line with the Convention, Nepal’s own Disability Rights Act of 2017 has made significant departure from the welfare-based approach to the rights-based approach to disability, recognizing the intersectionalities³ within disability, and eliminating derogatory narratives and even criminalizing the use of such narratives.⁴

Women and girls face structural and systemic barriers to be able to fully enjoy their reproductive health and rights and be safe from any form of violence. The information and services related to Sexual and Reproductive Health (SRH) are either not accessible to them, or their socio-cultural context does not let them make use of existing facilities.^{5&6} This gets more complicated for women with disabilities. Women with disabilities in Nepal

1 Nepal. I., (2017). Exploring the use of the internet among gender equality and sexual rights advocates in Nepal. EROTICS South Asia exploratory research: Sex, rights and the internet

2 Preamble of the UN Convention on the Rights of Persons with Disabilities, 2006

3 The term “intersectionality” considers the intersections in our identities – both that are self-defined and which further develop and evolve because of our interactions/experiences with others, and that which are internalized as our own meanings but given, passed down, taught, told, reinforced, dictated by others through political, social, economic and technological institutions.

4 (2018, February 20). Committee on the Rights of Persons with Disabilities reviews the report of Nepal. OHCHR. <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=22676&LangID=E>

5 Morrison, J., Basnet, M., Budhathoki, B., Adhikari, D., Tumbahangphe, K., Manandhar, D., Groce, N. (2014). Disabled women’s maternal and newborn health care in rural Nepal: A qualitative study. *Midwifery*, 30(11), 1132–1139. <http://doi.org/10.1016/j.midw.2014.03.012>

6 Devkota, H. R., Murray, E., Kett, M., & Groce, N. (2017). Healthcare provider’s attitude towards disability and experience of women with disabilities in the use of maternal healthcare service in rural Nepal. *Reproductive Health*, 14, 79. <http://doi.org/10.1186/s12978-017-0330-5>

face discrimination and are mistreated when accessing these services.⁷

Interviewee: Not much conversation happens around bodies of PWDs. PWDs' sexual life is in the shadows. Sexual life is not their priority. For their parents, it's not their priority. For PWDs, the primary need is something else. For instance, the access to education, employment etc. Some of them don't even have basic support. That's why.

Studies globally have shown that WWDs are denied access to sexual and reproductive health services at a much higher rate than their abled counterparts.⁸ In addition to this they face very specific forms of violence related to their disability.

The legal capacity of women with disabilities is diluted in multiple legislations. Section 3 of the Civil Code (Muluki Aparadh Ain) 2017 of Nepal on Family laws, article 71.2 nullifies any marriage if anyone is 'fraudulently' married to someone who cannot speak or hear at all, is blind, or is with severe intellectual disability.

No one shall conclude, or cause to be concluded, marriage with a man or a woman on any of the following conditions, by way of misrepresentation: (a) One who has contracted human immunodeficiency virus (HIV) or Hepatitis 'B' or similar other incurable severe disease, (b) One who has already been proved to have no sexual organ, to be impotent or to have no reproductive capability, (c) One who is dumb or has lost hearing capacity, being fully blind or is suffering from leprosy, (d) One who is of unsound mind, (e) One who is already married, (f) One who is pregnant, (g) One who has been convicted of a criminal offense involving moral turpitude by a court and sentenced for the same.

(3) A person who is aggrieved from the conclusion of marriage by way of

misrepresentation pursuant to sub-section (2) may get such a marriage voided and claim a reasonable compensation from the person who concludes, or causes to be concluded, marriage by misrepresentation.

Given the existing power structure of our society where women are marginalised, such a law puts women with disability at risk. The law has the potential to be misused by individuals who may later claim that they were unaware of the disability of their partner. Given the Nepali judiciary's record in prosecuting violence against women, the law makes women with disabilities vulnerable to malafide prosecution, even if they and their partner had originally married with consent. This goes against the Rights to Article 23 of UNCRPD that specifies PWDs right 'to marry and to found a family on the basis of free and full consent of the intending spouses is recognized'.

Section 6 of the Privacy Act 2018 on privacy relating to reproductive health and pregnancy considers matters relating to reproductive health and pregnancy of all women private, however such information could be shared with the guardian or family if they are of 'unsound mind'. Language such as this restricts the rights of PWDs to the ones "granted" to them by their guardians/caregivers. This is tantamount to having one's privacy based on the diagnosis of one's mental state and thus does not respect the autonomy of individuals to understand their bodies and make decisions about it. It also assumes family and guardians always make decisions which are in the best interests of PWDs, whereas studies have shown that there is a high rate⁹ of domestic violence and intimate partner violence among women with disabilities as well. While there are developments and small positive steps in the legal landscape of Nepal, women with disabilities remain highly under-recognized, and many of the issues related to disability are largely absent from the wider

7 Kayastha, S. (2016). Sexuality of women with physical disabilities: Experience and realities [Masters dissertation, Tribhuvan University]. Tribhuvan University Library.

8 Mantsebo.T. (2018 September 26). Sexual and Reproductive Health Rights for Women with Disabilities. Girl's Globe. <https://www.girlsglobe.org/2018/09/26/sexual-and-reproductive-health-and-rights-for-women-with-disabilities/>

9 Women Enabled International. <https://www.womenenabled.org/violence.html>

discourse on social inclusion in Nepal.¹⁰ Besides a few instances of inclusion issues around needs and challenges of WWDs in the Sexual and Reproductive Health and Rights (SRHR) movement, other large movements in Nepal also based on inequality and marginalization like the indigenous movement, Dalit movement, youth movement and LGBTIQ+ movements have not incorporated the agendas of PWD from within their own communities. Lack of intersectionality in the discourse within each of these movements limits spaces for WWDs to bring forth and address multiple marginalizations they might have.

This sentiment has been shared by a number of individuals in the disability movement in Nepal. During the SAWF Fund Convergence 2017 (South Asian Feminist event) indigenous rights activist Chini Maya Majhi shared how women are seen as a homogeneous group, without accounting for the diversity within them. According to Chini Maya, indigenous women and women with disabilities (WWDs) still find it difficult to integrate their issues within the (mainstream) women's movement as well as in the indigenous movement and disability movement respectively.¹¹

Similarly, Sarita Lamichhane in her article¹² writes about how organizations that work for young people are not inclusive of young people with disabilities when it comes to providing employment, or designing materials, websites and spaces where they mobilise young people, such as at demonstrations. She further writes, people with disabilities are not seen as capable advocates of any issue beside the issue of disability itself. Even when they are included, it is often mere tokenistic.

Pratima Gurung, a feminist disability rights activist, writes:

“Intersectional discrimination begins first from the family itself for women with disabilities (WWDs), pushing her life towards deprivation, pessimism and isolation. Slipping lower and lower in the social hierarchy, they are most of the time perceived as ‘unwanted and unproductive human resources’ and are silenced. Having no social security, lack of response from the government, lack of identifying and sensitizing on the rights and service delivery for WWDs both in the private and public sphere, WWDs are ‘excluded within exclusion’.”¹³

For women with disabilities, the exclusion faced by a disabled body in an ableist world is compounded by the exclusions faced by women in a patriarchal world.

Our objectives

This study is a glimpse into the lives of women activists with disabilities who are living with multiple deprivations given Nepal's structural injustices. This report includes diverse narratives of ways in which disability rights advocates are using the internet, whether in their personal lives, to explore and express their sexualities, or for their activism. We aim to shine a light on individuals who have been ignored in mainstream discourses on women's rights movements, sexual rights movements, and conversations around technology.

This research probes disability rights activists' comfort with the language and concepts of sexuality and sexual rights, their perceived needs

10 Lord, A., Sijapati, B., Baniya, J., Chand, O., & Ghale, T. (2016). Disaster, Disability, & Difference: A Study of the Challenges Faced by Persons with Disabilities in PostEarthquake Nepal. Published by Social Science Baha and the United Nations Development Programme in Nepal: Kathmandu. https://ia801605.us.archive.org/28/items/DisasterDisabilityDifferenceMay2016/Disaster-Disability-Difference_May-2016.pdf

11 South Asian Women's Fund (SAWF) Convergence 2017, Kathmandu, Nepal, Notes from the session “Building Inclusive Movement”

12 Lamichhane, S. (2020 August 15). Youth Day and Social Mentality(युवा दिवस र सामाजिक मानसिकता). Saral Patrika <https://saralpatrika.com/content/33817/2020-08-15?fbclid=IwAR074-TrxwA3M4JK9jc6vfOzf2WNo1t3rKQp0-CGJ7rXkL4qmmHCFChqnxU#.XzdYhsL4qGY.facebook>

13 (Gurung 2010: ii)

in the online space, online harassment of women with disabilities, and areas where support is needed. The primary objective is to sketch a rough map of the landscape, and indicate any major gaps and breaches that prevent women with disabilities from exercising their freedom of expression as citizens, or engaging in advocacy work as activists online. Where possible, we also focus on sexual expression of women with disabilities and their advocacy work on sexuality, including sexual and reproductive health rights.

The disability rights movement in Nepal was initiated and is still led by mostly Brahmin cisgender men, and women's rights issues within the disability movement is led mostly by Brahmin cisgender women. The movement is based on the principle of equality which focuses on providing equal access and opportunities and ensuring rights of PWDs. Though the movement has also recognized special needs and provisions required by the community, it mostly revolves around what they consider basic needs and requirements, keeping sex and sexuality secondary. Within the disability rights movement, a lot of emphasis is given to employment opportunities and is thus linked to education, revolving around the theory that PWDs are made 'abled' to work professionally despite their disabilities, and that financial independence will help empower them.

Lately, women disability rights activists have started flagging the need for focus on sexual and reproductive health for the communities of PWD, along with addressing and curbing sexual violence they face. However, the way in which sexual and reproductive health concerns are raised in Nepal revolve around heteronormative Brahminical ideas of marriage and motherhood. A common refrain within Nepal's mainstream women's rights movement is a heavy focus on demand for protection from violence, as opposed to other dimensions of agency and autonomy. These ideas are carried over into disability rights activism as well. There is also a constant tendency to compare with able bodies. The disability rights movement

demands the same things able-bodies receive. This is an "equality" focused lens, where the rights being demanded are already limited to begin with (rights formulated by and for abled bodies), rather than seeking alternative forms of defining ability for bodies of PWD, and exploring what they are capable of on their own, beyond comparison.

For women disability rights activists, these conversations can be very complex; WWDs are seen as unmarriageable or asexual, and thus their fight for visibilising WWDs as worthy of marriage is often the first step in actualising their sexual rights, even though fixation on "marriagability" restricts a broader concept of women's autonomy.¹⁴

While our work was focused on sexual expression of PWDs in the online space, our conversations unearthed many other "basic" needs that our discussants emphasized – which points to a hierarchy of rights within the disability movement.

PWD have multiple exclusions to fight, whether it is inaccessible public services, lack of education, lack of employment opportunities, or discrimination within family and society. Against this backdrop, sexuality and digital rights are seen by many as a "luxury" or a secondary problem. Our research also shows that there is little to no work done in Nepal that focuses on PWDs sexual expression or digital rights in the country, let alone the intersections of these two spaces – online sexual expression. This is an indicator of how low these issues are prioritized within the disability movement. Technology is also often discussed in relation to PWDs only in terms of access, considering them as beneficiaries.

Body & Data emphasizes exploring issues of digital rights from the perspective of communities who are marginalized by the state and social structure. Disability has been one of the intersections we try to bring in wherever we can, in terms of skills and knowledge we

14 Banerjee.P. (2017 January 8). Disabled Women are not thought to be wife material by many. The Hindustan Times <https://www.hindustantimes.com/india-news/disabled-women-not-thought-to-be-wife-material-by-many/story-QMqdQ4CS043GQg5diavRGL.html>

have. While there is some understanding among digital rights and tech groups that PWDs need to have access to the internet, this also limits the conversation to PWDs being end-users only. At Body & Data, we seek to look into how ableist views and perceptions of disability perpetuate in any technologies or platforms. Learnings from the disability justice movement inform our analysis of national policies and our advocacy work. We seek to take into account how the community expresses themselves online and how they are perceived, and discuss accessibility not only in terms of gadgets and internet but look into other barriers which prevent PWDs from using them with autonomy. Body & Data board member Sarita Lamichhane is a disability rights activist who has been crucial in providing suggestions for making our strategy and program accessible and conducive to PWDs. Some of the Body & Data staff also have previous experience working with disability rights groups.

This research project is an important step for us as an organization to understand the intersection of disability, sexuality and technology further, and integrate these findings into our ongoing and future strategies.

Methodology and limitations of the study

This report is built on individual narratives and lived experiences of women activists with disabilities.

A combination of 16 in-depth interviews and two focus group discussions were held with disability rights activists based in Kathmandu, all of whom identified as women. The 16 in-depth interviews that included 14 women disability rights activists and 2 queer rights activists with disability were important in bringing out rich personal experiences of their encounters with sexuality issues and digital spaces.

The interviews were complemented by two focus group discussions which provided the larger context in which the individual experiences were taking place. The FGDs conducted had the

participation of 22 individuals (12 in one FGD and 10 in the other). FGD is a useful method in flattening the power dynamic between the researcher and participants, and for encouraging the group to talk about sensitive issues more openly. The two FGDs were important in providing clues to the issues that the WWD activists saw as important, and also helped the group get comfortable discussing issues of sexuality with each other. This then helped generate new ideas on how the work could be taken forward as a community.

However, the combination of qualitative methods we chose is not without limitations. Focus group discussions, and to a lesser extent, in-person interviews on these issues are not anonymous, and tend to result in more conservative responses on taboo issues such as sexuality. As will be seen in the body of this report, speaking openly about sexuality in Nepal is taboo and many do not even discuss these issues with their closest friends, let alone strangers. In focus group discussions, as well as key informant interviews, participants initially hesitated to speak up and share matters of sexual pleasure such as viewing porn. These conversations were accompanied by giggles, silence, as well as occasional expressions of disgust, although people got bolder as the group moved deeper into the discussions.

The disability rights activists who comprise our respondents for this study all have their own cellphones, all live in Kathmandu Valley, and all were contacted via individuals or organizations in the disability rights movement in Nepal. Hence their experience is not necessarily an indicator of the general population of persons with disabilities in Nepal. For example, a telephone survey conducted by SINTEF Technology and Society in 2016 in 59 districts in Nepal found that many persons with disabilities are still out of reach of modern technology. In the study, according to data from 2000 households with disabilities, only one-fourth of the respondents with disabilities in the telephone survey had basic knowledge of computers, and only three-

fourths were independently operating mobile phones.¹⁵

This research provides a glimpse into the experiences of a more formally educated, urban subset of persons with disabilities. The issues of access, discrimination, and silencing faced by them can thus be assumed to be multiplied for other persons with disabilities in Nepal that do not have these privileges.

Another limitation relates to the handover between researchers that happened in the course of the research. One researcher conducted the interviews, the qualitative data was translated and transcribed in English, and working from these transcripts, a second researcher worked on the narrative. We acknowledge that some of the nuances and contextual information of the actual discussion might have been lost in this process, though we have put utmost effort towards mitigating this.

Feminist Ethical Principles of Research

Feminist ethical principles have guided our research. One of the cornerstones of research guided by feminist values is having a process that goes beyond informed consent.¹⁶ Through focus group discussions and interviews that are centered around personal experiences, with the discussants as experts in their own lives, the researchers aimed for an environment where all views are given adequate time and value.

Another element has been acknowledging positionality on the part of the researchers, where researchers “reflect on their own position and location in relation to their research participants.”¹⁷ Such reflexivity helps researchers explore how what we choose to study is a reflection of our own views and experiences, and an expression of our solidarities. In choosing to explore the online experiences of women

activists with disabilities, Body & Data builds on its prior experiences working in digital rights, as well as our experience of working closely with disability rights activists on various issues.

In our research we consistently focus on the subjective and diverse lived experiences of our collaborators, how they navigate the world online and offline, and challenge patriarchal and ableist power structures in their own individual ways.

15 Eide. A.H, Neupane. S, Hem. K.G. (2016). Living conditions among people with disability in Nepal. SINTEF Technology and Society. <https://www.sintef.no/globalassets/sintef-a27656-nepal-printversionfinal.pdf/>

16 Jenkins.K, Narayanaswamy. L, & Sweetman.C. (2019). Introduction: Feminist values in research, Gender & Development, 27:3, 415-425, DOI: 10.1080/13552074.2019.1682311

17 Ibid.

Operational definitions

SAFE SPACES:

For the purpose of the study ‘safe space’ is defined as a place or forum where individuals who are marginalized come together to communicate their experiences without the fear of being judged, trolled and attacked while also recognizing structural oppressions and systems of power.

SEXUALITY:

For the purpose of the study, sexuality has been defined as the way people experience and express themselves sexually which includes biological, erotic, physical, emotional, social, or spiritual feelings and behaviors.¹⁸

“The right to sexuality on/in the internet is a way of expressing the self and represents at the same time exploration, affirmation, resistance and transformation. We all need to understand it and stand by it. Support should not be denied and should be the political practice of any advocate. And this is when a feminist perspective of intersectionality, solidarity and transformation helps to orient us in the noise generated by the overwhelming horizontally participatory conversations enhanced and amplified on/in the internet.”¹⁹

18 Human sexuality. (2019, April 8). In Wikipedia. https://en.wikipedia.org/wiki/Human_sexuality

19 vale, h. (2017). In plain sight: On sexuality, rights and the internet in India, nepal and Sri lanka. In APC's EROTICS South Asia exploratory research: Sex, rights and the internet (pp.11) https://www.apc.org/sites/default/files/Erotics_1_FIND.pdf



A spectrum
of access

A SPECTRUM OF ACCESS

While the potential exists for specially assistive technologies in vision, communication, mobility and learning to significantly increase accessibility for PWDs²⁰, their potential is a long way from being realized.

Access issues include unequal access to devices such as mobile phones. A study of information and communication technology use by persons with disabilities found that only 32% of PWDs have access to a mobile phone. Of those without phones, 65% pointed to their disability as the reason they did not own a phone.²¹ Though Nepal stands in 13th place²² in the list of countries with cheapest internet, the cost is still high for citizens given the per capita.

Even when PWDs do have access to the internet, online worlds are not built with their needs in mind. In the context of Nepal, social dynamics such as caste, gender, sexual orientation, race, age, language barrier and economic class also come into play as causes of exclusion.

After advocacy from disability rights groups, the Nepali government has been providing discounted voice packs for the visually impaired if they submit their disability identity in the telecom office. However, barriers still exist as they range beyond just issues of affordability. For people with disabilities, accessibility is not just a concern regarding existing and available technologies, but also the support needed for PWDs to learn to effectively use and navigate these digital technologies. For them, both the hardware and the skills to use them are assistive aids in an inaccessible world.

Our own research showed how the online world's default settings exclude PWDs. When we reached out to PWDs with our quantitative survey, only six people managed to participate. In order to be able to include a larger number of voices of PWDs, we had to design an additional component, with in-person visits and the requisite attention to translation and other support needs. Our participants also noted how these conversations around PWDs' access to the internet are not a part of policy discussions.

One of our participants noted that having access to the internet doesn't always mean that everyone accesses it equally; questions about how they are accessing it and where they are accessing it are also important.

Having access to the internet often means having certain prerequisites: a certain socio-economic background, or having employment and connectivity at work, or being from an urban area that has internet infrastructure.

In charting the evolution of socio-cultural norms around ability and disability in Nepal, a review undertaken by the National Federation of the Disabled-Nepal explores the shifting of perspectives from prejudice towards PWDs to seeing them as "beneficiaries of charity, and services for which they should be grateful."²³ The authors conclude that this results in services that are "designed for them and delivered to them, perhaps with the best of intentions, but with insufficient consultation."

Within the disability movement itself, the charity model is heavily criticised because it is assumed that people with disabilities must be "content"

20 Lamsal.R.R, Pathak. S, Nepal. S, Bomrel. M. (April 2019) Exploring ICT in Empowering Persons with Disabilities in Nepal. Deerwalk Journal of Computer Science and Information Technology. 1, 64-77,

21 Samarajiva. R. (2018).ICT access and use by Persons with Disabilities (PWD) in Nepal. AfterAccess. <https://g3ict.org/publication/ict-access-and-use-by-persons-with-disabilities-pwd-in-nepal>

22 Atlas and Boots. (2020).Countries with the cheapest Internet in The World,. <https://www.atlasandboots.com/remote-work/countries-with-the-cheapest-internet-world/>

23 National Federation of the Disabled(2013). Disability Rights Holistic Monitoring Report.Nepal. <https://nfdn.org.np/holistic-report-of-disability-rights-monitoring/>

with what they “receive”. The charity model also created a dispute at the national level, in the “prevalence of disabilities,”²⁴ where the government has come up with a low prevalence rate, which is shown by NGOs and self-help organizations’ work to be an undercount. The human rights model of disability recognises disability as a natural part of human diversity that must be respected and supported in all its forms.²⁵ It posits that the exclusion happens because of a disabling environment. Hence, changing the environment should not be understood as something “given” to people with disabilities but inherent in their rights.

Social barriers, discrimination and exclusion keep PWDs from participating fully in their society. They face barriers in access to transportation, education, employment, health services, and rampant discrimination with 72% of unemployed persons with disabilities and 56% of employed persons with disabilities reporting that “they have no dignity in social participation.”²⁶

Whether it is doctors routinely denying sexual and reproductive health services to PWDs, not having information tailored to PWDs, or constant judgment for making any choice regarding their body and self expression, PWDs face many hurdles when it comes to accessing information and services. For persons with disabilities, self expression and sexual expression offline are subject to constant judgment, discrimination and even ridicule.

While the online space can provide alternative forums for self expression in safe spaces and groups of other PWDs, many of these offline discriminations inevitably find their echoes in the online world. PWDs are harassed in mainstream online spaces, there is lack of content tailored to PWD needs, they face inaccessible technology and myriad other challenges daily. Cultural perspectives towards girls and women in Nepal are steeped also in protectionist

lens, fixating on the assumption that they are vulnerable to violence. There is a tendency to perform overprotective parenting. Against this backdrop, girls and women with disabilities face additional barriers in using the internet freely without constant surveillance on their online behavior from family and caretakers. In these circumstances, them accessing materials related to sexuality and expressing one’s sexuality online becomes challenging, despite access to the internet.

Our interviewees shared several experiences of encountering barriers to full access while on the internet. One of the interviewees who used a screen reader shared:

“I can read the words in English but I can’t read Nepali words completely. Plus, in order to read a pdf, another app is required. So, everything cannot be seen nicely. Sometimes, when people upload pictures, the app doesn’t dictate it. It only says that there’s a photo but we cannot know about the photo, like what the photo is about.”

She also shared that accessing websites in Nepali language is harder for the screen reader, resulting in her and many other blind and vision impaired users visiting fewer websites on the internet.

For deaf and hard of hearing users the problems are different. One of the interviewees shared this concern about overwhelming English usage on the internet and her preferred fluency in Nepali. She said:

“I want to learn how to use Twitter. I have heard what I can post there. But since [the discussions there are] mostly in English, I don’t want to have miscommunication because I don’t know English that much. I haven’t learnt it at all. Because I don’t want to spend my entire day on the phone, I don’t use it as often. It’s mostly Facebook, messenger, viber and sometimes skype

24 Ibid

25 Introducing a human rights model of Disability. Disability Advocacy Resource Unit. <http://www.daru.org.au/how-we-talk-about-disability-matters/introducing-the-human-rights-model-of-disability>

26 National Federation of the Disabled(2013). Disability Rights Holistic Monitoring Report.Nepal. <https://nfdn.org.np/holistic-report-of-disability-rights-monitoring/>

because of work. Internationally, skype is used for meetings so I use it.”

While using the internet to talk about their daily lives, the women shared that they used Facebook, Twitter and others platforms to post things. However, a few of them shared that there was a lot of miscommunication because of language barriers, especially for deaf and hard of hearing women.

One woman shared how her access to the internet was mediated by her husband. This isn't an uncommon experience for WWDs. She shared:

“I mostly share all my arts and paintings on the internet. He (husband) tells me to concentrate on my work and that he'll look after the (social media) posts. He does most of these activities for me. I talk to my foreigner friends online and do video calls on Messenger. I have so many friends from India. They are from Bangalore, Mumbai and Delhi. There are many deaf people there. I talk to them on video call. They share things with me. This doesn't happen in Nepal.”

Another shared how the internet led her to access community but her husband restricted this access eventually.

“I have the desire to search things related to art. I see and use the internet. And I also research about what's going on in the deaf sector (community). Previously when I was in college, I said that I would use signs to communicate but he (husband) told me not to use it (with anyone). I have my own community. I should be able to use it in my community. He could not understand it so we had arguments.”

While these comments are only about accessing and using the internet in general, the problems with accessible content on sexual and reproductive rights for women with disabilities

is more complex. In an interaction with the interviewer, a woman with disability shared:

Interviewer: Do you really think the information that is provided on the websites are effective and has enough content about sexuality?

Interviewee: Not sufficient. Sometimes people interpret in a very negative way and the materials are not even sufficient to express more about it. When we talk about porn they can't be associated, like those without visual impairment can access it easily but for others (visually impaired), audio is not enough.



Sexuality and bodies of PWD-
a culture of silence

SEXUALITY AND BODIES OF PWD—A CULTURE OF SILENCE

Ani Phoebe Hao imagines the kind of digital world we deserve; a world “where we have more than our rights; we also have the pleasure to enjoy our identities, practice our sexualities, meet new people, access information and make informed decisions about risks and pleasure.”²⁷

This is an ideal that this research is also guided by. However, a wide gulf exists between these aspirations and Nepal’s ground realities. Far from a discussion on women’s pleasure and freedom of sexual expression, Nepali society is one where even health issues related to women’s sexuality and reproduction can be taboo topics. Amidst this, talking about sexuality of women with disabilities is so radical as to be unthinkable.

Perhaps the environment in which the research took place can be best summed up by a participant who shared:

“Didi, we live in a society where we cannot even talk openly about (something being simple like) menstruation, talking openly about sexuality is a dream that is very far from reach.”

Similarly, other participants too shared the discomfort they felt, in response to why conversations on sexuality were not taking place in their circles.

“Our context is such that women in Nepal are not able to talk about sexuality openly. Even as activists, we are not able to talk about these basic health issues such as white discharge, let alone issues of sexuality.”

“[We are informed about a lot of things regarding sex and sexuality] but it is hard

to talk about these things openly.”

“Well the thing is no one really shares such information to others although they go through such articles.”

Women with disabilities we spoke to focused on how being women in a patriarchal world constrained their ability to have conversations about sexuality. Like in many other societies in South Asia, paternalistic notions of honor, respect, and purity are attached to women, and are used to police women’s sexual freedom and reproductive health in Nepal.

“It is very awkward to talk with friends about sex and sexuality in the context of Nepal. I can’t talk with anyone. In my case I can’t talk with my husband either. Most of the time I watched porn with my husband. Actually, he taught me to watch porn. But when we divorced, he blamed me for being a characterless girl who watches porn. We live in a country where talking about sexuality is prohibited.”

Explicit conversations around sex and sexuality are not easy given Nepal’s social circumstances. In addition, the disability rights movement in Nepal is led by high-caste Brahmin men, campaign agendas are set by them, and sexuality is not regarded as a priority within their framework. The welfare approach from the state, along with rights groups focus on rights based approaches²⁸ adopted lately still do not favor taking an intersectional look into the issues of women and girls within the movement.

Oppressive dominant discourses that result in women being discouraged to speak up about, explore, or express their sexuality are further

27 Hao.A.P. (2019 DEcember 4). Internet Freedom is Not Enough - Cyberfeminists Are Fighting For a new reality. GENDERIT. ORG <https://genderit.org/articles/internet-freedom-not-enough-cyberfeminists-are-fighting-new-reality>

28 See page 11 for further discussion on “rights based approach”

compounded for WWDs, who must contend with even more conservative expectations regarding the sexuality of PWDs. An added layer of paternalism is extended towards persons with disabilities, who are viewed regularly as objects of pity, needing support, and incapable of agency. This is seen in the widespread control of WWDs' sexual and reproductive health with forced hysterectomies, forced abortions and more across the globe.²⁹ In a report to the UN General Assembly in 2017, UN Special Rapporteur, Catalina Devandas said:

“Discriminatory laws and policies are undermining the fundamental right of girls and young women with disabilities to exercise choice and have control over their bodies, violating their integrity and depriving them of dignity while promoting the interests of professionals and caregivers instead.”

This reinforces what our interviewees told us about how their sexual rights are seen both within the home and in society at large. Those with disabled bodies are routinely treated as asexual beings, with the assumption that only able-bodied persons could have any interest or ability to participate in acts of pleasure. As shared by a participant:

“This subject isn’t considered important. No one thinks that disabled people also have physical need, they do not need sex and they do not have interest about sex. Sex is only for abled people. That may be the reason for not talking about sexuality. But we are raising voice for this.”

These social expectations and intersectional oppressions result in a fear of judgment and reluctance to speak about these issues. This was highlighted in this individual interview with a senior disability rights activist:

Interviewee: Just because someone has disability does not mean that the person doesn’t have sexuality. Disability has

nothing to do with one’s sexuality. These are two different things.

Interviewer: Have you ever shared these sentiments on the internet?

Interviewee: No.

Interviewer: Why not?

Interviewee: It’s like people might start looking at you differently. People pass negative comments so I learn these things that I need to learn, but do not post them on social media.

Interviewer: Why?

Interviewee: I feel like people will make negative evaluations, that’s why.

Interviewer: But, you are also the chairperson of the organization right?

Interviewee: Umm... Umm

Interviewer: You have this strong identity. And a lot of people on Facebook might also know that you are working on reproductive health all but why do you have the fear?

Interviewee: This is a strange thing. We know that these things are hidden and not talked about much in society. We should take it as a simple thing. Just like food, shelter and clothes, it is also one of the basic needs. Even if we are talking about these in friends circle, it is still hard to open up on these topics.

It is difficult to move beyond the dominant discourse on disability and sexuality of PWDs as asexual beings—and to acknowledging their sexuality being as normal as anybody else in society.

Being seen as either asexual or hypersexual

Across the world, disabled bodies are seen as not desirable, too defective to engage in sex. In Nepal, WWDs are often treated as if they are asexual, with the added assumptions that they

29 (2017 October 24). Forced sterilization of young women with disabilities must end, UN rights expert says [White Paper]. OHCHR. <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=22289&LangID=E>

are incapable of engaging in a sexual relationship, and unable to bear and raise children.”³⁰

Thus when PWDs engage in any expressions of their sexual selves, this goes against general expectations, and the pendulum swings to the other side with them being perceived as hypersexual. When forced to choose between society’s binary of being asexual or hypersexual, many of the participants in our study choose to err on the side of the identity that comes with lesser social risk i.e. being seen as asexual. Participants avoided talking about their identities as sexual beings online, to prevent the negative repercussions of being labeled hypersexual. This was, in many ways, a strategy for survival.

Hypersexuality is a charge that is regularly levied against women who so much as acknowledge that they have sexual desire, even within the confines of a married relationship. This patriarchal narrative where a woman’s sexual desire can easily be rephrased as a negative comment on her character has routinely been used by men to shame women. Being a WWD of whom asexuality is the expected norm makes accusations of hypersexuality stick even stronger.

The net result of all these microaggressions is rampant self censorship, which has been an overarching theme throughout this research. Participants, when speaking of their experience, routinely described strategies of not attracting unwanted sexual attention to themselves, and censoring themselves on social media in order to escape negative attention. When, during a focus group discussion, one of the participants said,

“We don’t really put anything like that out there that would attract negative comments,”

...the agreement in the room was palpable.

The lack of WWD-led narratives online also contributes to the issue of sexuality and disability remaining hidden – without models of

WWD discussing sexuality online, it is difficult to make space, even in the imagination, for discussion on these issues.

When speaking about these implicit things in society, there is an understanding it will raise controversy. So even though these conversations are deemed important, there might be other agendas that activists are working on that they do not wish to risk. Their community or circles might require them to ensure that they do not raise issues that will invite “negative comments” or cause people to “start looking at [them] differently.”

The fear of being deemed hypersexual, and the subsequent loss of one’s credibility carries a high risk, especially for those engaged in activism.

If acknowledgement of sexuality of women and PWDs is hard to come by, conversations on pleasure and sharing of pleasurable content is even more so. The following was shared by a participant, almost as a confession:

“I myself watch such things (talking about porn) but I can’t tell even my closest people to watch it. (laughs)”

The social “conspiracy of silence” around the sexuality of WWDs is strong. Something as natural as sexual pleasure itself is made to seem like an indulgence, and confessions of being engaged in sexual pleasure run the risk of judgment.

Changing times

All our participants quoted so far have demonstrated how the internet has been a source of information on sexuality, sexual health, and a source of sexual pleasure. Most of our discussants had been part of conversations around disability and sexuality in formal or informal settings. They spoke of the need to have wider acceptance for PWD’s sexuality, and were conversant on sexual and reproductive health rights as well as issues of consent. Since this information is hard to come by from other

30 Kayastha, S. (2016). Sexuality of women with physical disabilities: Experience and realities [Masters dissertation, Tribhuvan University]. Tribhuvan University Library.

sources owing to lack of open conversations on the issue in relevant circles, the internet has been valuable for those able to access it.

However, access is not a given, especially for those with disabilities, and content is not always tailored to their needs. In addition, simply accessing information is not enough; for meaningful change to occur, public conversations on pleasure and consent need to happen.

As stated by a participant:

“Sex is a need but it should be engaged in with mutual consent. But girls are not talking about this topic, because if they talk, other people start to see them negatively.”

In this manner, assumptions that associate willingness to talk about sexuality, pleasure and consent with being promiscuous lead to fears of social disapproval, which in turn prevents consensual, mutually beneficial exploration of pleasure.

Some respondents shared that the internet is slowly helping these conversations take place among WWD. In their own words, a few interviewees described talking about these issues as a sign of openness (“frank”), as opposed to the social tag applied to it as being provocative or immoral.

“The internet has changed this context a lot.”

“I know a lot of information from online sources. I am very frank about these issues.”

Our participants also emphasized that having these conversations is important in another way:

“Nepal Disabled Women Association (NDWA) has now been talking about sexual and reproductive rights. Before that, with regards to even something like marriage [in terms of marriage advocacy for PWD], I could not even envision that I myself could be married. But now I am in a

happily married life.”

This anecdote is an example of how conversations about disability and sexuality can broaden the range of futures that a woman with a disability is able to imagine for herself, whether that future includes marriage, a family and sexual pleasure or not. There is a need for more spaces to have these conversations and open up more possibilities for expressing one’s sexuality and visibility online.

While the internet has provided a platform for discussions about sexuality, participants emphasized that these discussions are not happening, and that they are not using the internet for sexual expression.

There could be multiple reasons for this, chief among them a narrow understanding of the word “sexuality,” and “sexual expression.” In fact, we found in our research that quite a few activists did not think they were engaged in conversations about sexuality online, even as they spoke of instances of sharing content related to their attendance at conferences on disability and sexuality.

In addition, a large number of participants shared the multiple ways in which they engaged in self-expression and exploration of pleasure online – including sharing beautiful photos, videos of singing and dancing and other explorations of beauty and pleasure, while not labeling them as expressions of sexuality.

Discussing sexuality

Even when people do want to talk about these issues, they find the language difficult. As with the English word sexuality, which because of “sex” at its root is regarded as a delicate subject,³¹ the Nepali word for “sexuality” is translated as “younikta” (यौनिकता) with “youn” at its root – which is also “sex” but with an even stronger connotation of being just sex and nothing else.

In addition, the word is a relatively recent import adapted from English and not part of everyday

31 vale, h. (2017). In plain sight: On sexuality, rights and the internet in India, nepal and Sri lanka. In APC’s EROTICS South Asia exploratory research: Sex, rights and the internet (pp.13)

speech or writing. As such, there is no common cultural understanding of the word and concept of “younikta.” As we saw time and again, it is also understood by most research participants to have a narrower definition, as something directly related to the physical act of sex, rather than to a person’s daily physical, cultural, or social expression as a sexual (or asexual) being.

These twin issues connected to the word “younikta” mean that in Nepali society, the word is already quite charged with assumptions of decency/indecency. Further, it is also likely to invite accusations of imported activism. This complicates our understanding of what our research participants are telling us, requiring us to go beyond the word itself to understand the phenomenon. A more expansive term that can bring together concepts of beauty, appreciation, self expression, self exploration, and reproductive health is unavailable for these conversations yet.

For example, participants were unanimous in emphasizing that discussions about sexuality are not occurring and repeatedly pointing out the strong societal reluctance to discuss sexuality. While this undoubtedly exists, many also asserted that even though they were activists leading the work at the intersection of disability rights and sexual and reproductive health rights, they themselves were not able to engage in online discussions of sexuality.

However, a few of these conversations indicate otherwise. A glimpse of this in this interview with a disability rights activist working on issues of sexuality:

Interviewer: Do you post about sexuality on Facebook when you are working on those issues?

Participant: It’s been 6 months of working on sexuality. I haven’t posted anything about sexuality.

Interviewer: When you go to different programs of sexuality and speak about sexuality, don’t you post that on social

media?

Participant: Yes, I do. I post if I give a speech or I participate in those programs.

Interviewer: That means you post about sexuality.

Participant: Maybe yes.

The exchange revealed another unspoken assumption in conversations about sexuality, that it probably has to do with one’s personal life and intimate details, and not one’s activism or public presence.

Another activist participant also shared how she put up photos of conferences on issues of sexuality, deliberately ensuring that the banner is fully visible. The participant, however, was unsure whether this counted as an example of her using online forums to share issues around sexuality.

These examples indicate an implicit assumption that discussions of sexuality are confessions of personal bedroom-related matters. Such an assumption makes, in people’s imagination, any discussions on sexuality fraught with a higher level of risk than is warranted.

As can be seen in the anecdotes above, our study participants felt that an acceptance by society of sexuality of WWD holds tremendous potential for richer, more fulfilling lives for women with disabilities, yet only minimal attention is paid to this issue. And when these issues are brought up and given attention, it is of the negative kind.

Safe spaces are starting points for robust discussions about disability and sexuality

Safe spaces (whether among friends, among colleagues who are working on the same issues, or in international conferences) were brought up by many participants as the only places where they can have discussions on sexual expression.

“I do not talk about these issues in front of men, but in this group, I can talk very

comfortably about these issues.”

“We mostly don’t talk about these kinds of topics. We sometimes talk about it in forums, because we can’t talk about it anywhere. We basically don’t talk about it [often], so, when it appears on the internet, I watch it.”

Participants also spoke of creating safe spaces for themselves online. They shared anecdotes on how they carefully curated their Facebook friends list to create safe spaces, accepting requests only from close friends, family, and the disability community. Thus, keeping themselves away from demeaning and judgmental attitudes towards women with disabilities that are encountered in the mainstream.

These responses indicate both a desire that these online spaces be able to host meaningful conversations around disability and sexuality, and a frustration that they have been unable to do so until now.

Of note is also the conflating of the internet with social media, especially for countries like Nepal where increase in access to internet coincided with the Facebook era. The internet subscription rate in Nepal is 55.6%³² and mobile users is 136%³³. When asked about their online experiences, all our respondents first shared their experiences on Facebook, indicating that the bulk of people’s online lives in Nepal are now spent on Facebook. In one of the focus group discussions, 9 out of 10 people said they used the internet, the 10th person said she used only email, implying she did not consider email as being “the internet.” The most common social media platform is Facebook, and Facebook Messenger is commonly used for communication within the community; statistics

show that Facebook alone accounts for 97% of social media usage in Nepal.³⁴

As we will see later in the report, the participants in our study used Facebook for a wide range of activities, including connecting with friends and family, making new friends, and getting updated on the news in general as well as disability issues in particular. However, the limitations of Facebook may also have contributed to discouraging online sexual expression. Facebook is a space where you can find your parents, employers, friends, lovers, along with all their expectations and judgments that can result in high self-censorship.

In the context of over reliance on Facebook by our cohort of interviewees, we are constantly reminded that:

“For a meaningful dialogue the space of the internet needs to be integrated, enriched and not limited or concentrated on social media.[...] They need respectful and ethically built spaces to host dissent and provide privacy, avoiding the performance and per-formative modality privileged by social media.”³⁵

Even though these issues are not as easy to discuss online, early and hopeful indications that they are happening are visible.

32 Internet World Stats. (2019). Asia Mobile and Broadband Report [Report] <https://www.internetworldstats.com/stats3.htm>

33 Nepal Telecom. (2020 May 24). Mobile, Broadband and Internet Penetration in Nepal. <https://www.nepalitelecom.com/2017/07/mobile-internet-broadband-penetration-nepal.html>

34 Pandey, S, Raj, Y. Free Float Internet Policies of Nepal. Studies in Nepali History and Society 21(1): 1–60 June 2016 © Martin Chautari (pp. 37)

35 vale, h. (2017). In plain sight: On sexuality, rights and the internet in India, nepal and Sri lanka. In APC’s EROTICS South Asia exploratory research: Sex, rights and the internet (pp.11) <https://www.apc.org/en/pubs/erotics-south-asia-exploratory-research-sex-rights-and-internet>

Use of the internet for self-expression by PWD



USE OF THE INTERNET FOR SELF-EXPRESSION BY PERSONS WITH DISABILITIES

“When I go to any programs, I post details about the programs and the fun with family members. If I go somewhere with my friends, I share about it as well... I use Tiktok too. I keep making videos. Most deaf people don’t use it. When I use Tiktok, I feel like I can hear myself and I feel like I am not deaf. So I use Tiktok and make videos.”

Self-expression and sexual expression were not seen as related by most of our study participants. While questions on sexual expression mostly revealed the frustration of not being able to have meaningful conversations online regarding sexuality of WWD, questions on self expression elicited a wider range of answers regarding online activities that our participants were engaged in.

When we understand sexuality and the erotic through Audre Lorde’s definition as a sense of deep fulfillment and full expression of a woman’s feeling and being³⁶, we are able to appreciate the wide range of ways in which participants in our study engaged in erotic expressions online, particularly on Facebook. This section attempts to capture the myriad ways our participants engaged in self-expression as well as sexual expression online, with the caveat that our participants did so without either considering or labelling them as sexual expression.

Most of our participants used Facebook for sharing personal messages such as birthday wishes. A majority of them also shared a lot of work related information, including upcoming job vacancies and training opportunities for the disability community. Apart from Facebook,

participants also reported using Youtube for inspirational songs, movies, and videos of persons with disabilities. A few shared that they used Google for studying and email for work.

Some of our respondents also shared how they were using Facebook as a forum for self-expression, sharing content around self-love and creative expression, as well as venting. As was described:

“I act, and dance, so I put up videos.”

“I share a lot of pictures in my status updates. I like to write also, so I write poems and such on Facebook. It feels good to post my pictures and writings. I write poems or other status updates about once a week and I use Facebook all the time. It’s like a friend to me.”

“When I get frustrated, or have something I can’t tell people face to face, I write and share on Facebook.”

Through Lorde’s lens that “blurs the boundaries between the erotic, on the one hand, and political, creative, and everyday activities, on the other,” we can look at these expressions as a “creative force for revolutionary change”.³⁷

Our research participants reported regularly using the internet for receiving information on beauty, sexuality and sexual health. Although only a very few understood these activities as falling under the umbrella of sexual or erotic expression, below are a few quotes from

36 Lorde.A. (1984). Uses of the Erotic: The Erotic as Power. Tucson, AZ: Kore press. https://uk.sagepub.com/sites/default/files/upm-binaries/11881_Chapter_5.pdf

37 Lorde.A. (1984). Uses of the Erotic: The Erotic as Power. Tucson, AZ: Kore press. https://uk.sagepub.com/sites/default/files/upm-binaries/11881_Chapter_5.pdf

participants that show the range of information that they got from online sources:

"I watch how-to videos on reducing acne, hair care and beauty routines. I get a lot of cramps, and look at how to reduce cramps. I learnt about hot water soaks, and eating chocolate, and how these help."

Here, our discussant reveals the multiple aspects of her erotic self that are important to her, and the variety of information on beauty, sexuality and reproductive health she seeks online to inform her in her goals of beauty and self care. Though most of such content online is not necessarily created with a WWD in mind, as long as WWD's physical disability is not a barrier to accessing this information, their experiences online have enriched their offline lives. Of course, most participants still had barriers to access, especially those with sight and hearing related disabilities, who could not benefit from a lot of such how-to videos and other content aimed at able-bodied women.

The need for content online that is tailored to the disability community is further demonstrated by this quote from another participant:

"...And many friends are exploring about sex toys. Many cases of married women who have spinal cord injuries have problems in sexual life. Even unmarried women do use sex toys generally in city areas more than rural areas."

The participant indicates how some forms of disability, such as spinal cord injuries, might close off the "traditional" routes of sexual pleasure through sex. When sex as an act is rendered difficult or impossible by a disability, sex toys provide an option for the fulfilment of one's sexual needs. Here too, those with a disability such as a spinal cord injury are able to access the internet with greater ease than those with hearing or sight related difficulties, and so are able to explore online options such as sex toys.

However, even for those who do not have problems accessing content meant for able-bodied people, the problem of representation is real. Being able to see oneself in the content that is online is a valuable experience that can make the space feel more like one's own.³⁸ The inclusion of PWDs in content-making also brings the possibility of addressing issues and experiences that are particular to disabilities; issues that are less likely to be on the radar of mainstream content creators.

One of our respondents also shared her experience of looking for porn videos, and being disappointed at not finding representations of bodies of persons with disabilities:

"I was looking for porn videos of PWD having sex, but I could not find any. We women with disabilities are seen as [...] asexual ..."

Porn, one of the earliest things that the internet became known for³⁹, still does not cater to those with disabled bodies. Our respondents also mentioned accessible porn, indicating that porn catered to an abled audience would not do.

Self-censoring the online persona

The activists in the research mentioned how they would use the internet for 'good' reasons given their public figures as activists and social workers. When probed further to elaborate, they stated that it involved sharing information and news about what is happening in the disability rights groups and communities, and talking about their work and events of their organisations. On the other hand, there is an understanding that sharing a lot of personal information, especially related to sad or distressing topics, is not encouraged; they feel

38 Moses.G. (2018 August 28). Why Disability Representation Matters (And not just in Media). The Body is not an Apology <https://thebodyisnotanapology.com/magazine/why-disability-representation-matters-and-not-just-in-the-media/>

39 Kusher. D. (2019 September 4). Brief History of Porn on the Internet. Wired <https://www.wired.com/story/brief-history-porn-internet/>

the need to be motivating and encouraging to PWDs in their online spaces.

“I don’t upload much as well. I mostly share inspiring things so that people can get inspired and learn something through them. I also share things that touch my heart.”

“People post things about suicide. Like how they want to kill themselves. There are times when they personally message me and share these things. This not only affects them but us as well in a very negative way. People should not share these things on Facebook. People should only share motivational stuff.”

“It was New Year’s Day when me and some of my friends had been to a club. I had shared it on Facebook too. The next day the head of the organization called me and told me that I should not be posting such things on Facebook. He told me that I am the leader of the future so I should not post such stuff. He told me not to post other personal pictures too. The ones not associated with the organization. I agreed with what he said about not to post clubbing ones but I could not agree with what he said about not to post my personal pictures. Ahh! It’s my choice. Totally!”

The belief that leaders in the movement need to be motivational for others in the community is also imposed within the community itself. Emotions related to sadness are seen as ‘negative’.

Participant 1: I also used to post a lot of pictures on the internet on a daily basis. Some of my sisters (colleagues from the movement) told me that being a member of the organization, I should not be posting a lot of pictures along with the captions [captions that conveyed personal feelings, including sad ones]. They told me that if I post such, then I will be taken negatively so I have been trying to post as less as I can. I control myself from posting pictures... They say, “Oh! You had posted pictures on the internet! Why???” They scold me. I know they say things that would be good for me so I don’t take it negatively. We are the people

working in an organization, there are lots of people who learn things from us. We should motivate them. I am still controlling myself. I am trying to improve myself.

Participant 2: It’s not that she can’t write. It’s just that the things that she’d write on the internet will be seen by her followers and they’ll get the wrong idea and message which further demotivates them. If you want to post photos along with a caption, do it but make sure that the caption is positive and good.

The pressure to share only ‘motivational’ and positive information on social media also restricts the participants from expressing their sexuality the way they desire.

“I had also posted a picture wearing a dress online and some people messaged me saying that I should not wear such dresses and that I look far better in jeans. I had neither worn that dress while going to work nor had anyone at work seen me wearing that in person. I had merely posted that online.”

“My husband and I had clicked a kissing picture which I uploaded on social media. My husband was against it and asked me why I posted such a picture on social media. I replied to him saying that it was a very precious moment so I posted it. I don’t know exactly when but later I deleted that post and yes, regretted [having to delete it]. Nowadays I am very careful about what I share and post online. Even if we post personal things, [our] organization is attached to it. So it’s crucial to be careful.

“Well the question is – being an activist we become careful and conscious about what we post online and we don’t post the things that we want to. We are not able to express it, right? Like I want to post a picture kissing my partner and that is part of my sexuality. So we are controlling our sexuality for the sake of activism... I might fancy to post hundreds of selfies that I love and that’s entirely my choice. But because of our work, activism and fear we [are not able to]...”

How disabled bodies are represented online

Narratives about bodies of PWD are replete with the assumption that their bodies are not just aesthetically ugly, but also functionally deficient, unable to perform important functions, especially reproductive ones.

The medical model of disability and “social construction of the impaired body as passive and dependent”⁴⁰ views disabled bodies as deficient and undesirable. These views about disabled bodies are further reinforced by views of women’s sexuality which has tended to dehumanize and infantilize women.⁴¹ These intersectional discriminations build on each other, leading to bodies of WWD being denied the respect, agency, and personhood afforded to other bodies.

Our research participants shared that, above all, their bodies are not even expected in online spaces. Many of our discussants shared how able bodied people are always surprised when they encounter someone with a disability online.

PWD frequently use Facebook and the internet but other people don’t know that PWD can also use Facebook.

Our research participants shared their experiences of uploading photos online, and getting negative comments, even from their Facebook circles of trust. These comments illustrate the kinds of bodies that women with disabilities in Nepal are expected to have, the way they are expected to carry those bodies, and also the lines that circumscribe acceptable forms of sexual expressions for WWD in Nepal.

Our participants reported receiving many messages of appreciation, which upon further examination, were not appreciation at all. Instead they were disclaimers that spoke of participant expectations that disabled bodies are not beautiful, and bodies that are beautiful cannot belong to PWD. “You don’t seem disabled”

seems to be the most common message that WWDs who fit conventional social definitions of beauty receive online.

For example, when asked what kinds of comments she receives on her photos, a participant said:

“Mostly appreciation. People say that my photos don’t seem like I belong to a community with disability. Sometimes I post pictures of me giving a speech, attending various programs, visiting different places. People say that I post beautiful pictures while attending programs. I post pictures of me when I go abroad as well. And, people get a shock. (Laughs)”

While at first glance this seems like a compliment and was taken as such by many recipients, there are various assumptions that the person who complimented internalized. One is that disability and beauty are mutually exclusive – so if the person has appraised you as beautiful, you cannot be disabled.

Another telling reaction is the one of “shock” on photos of foreign travel by a WWD, which also makes assumptions on the range of life experiences available to persons with disabilities. It is the compliment-giver’s expectation that those with disabilities cannot attend and give speeches at international programs.

In the same vein, another participant with a strong interest in beauty and makeup shared this experience:

“I used to wear full makeup earlier...and people did not think I was disabled. ‘When we look at you in photos...you don’t seem disabled (using derogatory words for disability)’ Are you trying to attract and confuse men?’ These types of comments come on Facebook and also from the (disability) community itself. I started deleting those comments, now I only have people from the disability community,

40 Christina S.A., Lucia S.A. (2017). Yes, we fuck! Challenging the misfit sexual body through disabled women’s narratives. Sage Journals. 21(3), 303-318. <https://journals.sagepub.com/doi/full/10.1177/1363460716688680>

41 Ibid.

and a few members from my family (on Facebook).”

Here too, we see how beauty and beautification is assumed to be irrelevant for disabled bodies. In addition, men seeing a beautiful woman through the hetero-normative ideas of desire and sexuality, upon finding out that she is disabled, assume that this must have been done on purpose, to get them attracted and confused. The participants often used language that marked clear binaries between beautiful and not, on the basis of body-ability, and they tended to think of themselves as unattractive.

How technology can facilitate expressions of sexuality

In addition to receiving information on sexuality, reproductive health, and engaging in discovery of sexuality through pornography, participants also shared that they have used the Internet as a medium for expressing their sexuality, whether in private chats or on online dating sites.

“Offline, there are no accessible places where we can go for dates or meet people. Before we meet someone, we are able to see their pictures, have video chats.”
“Basically people are not open about sex but they do sexual activities like video chat, sharing pictures. Some of my friends also do that but people don’t talk openly so real data about people exploring their sexuality on the internet is not available. The Internet plays a vital role for sexual activity among partners. It is easy, we don’t need to meet people, have physical contact and there is not any chance of having STDs. It is safe and private.”

These quotes show how offline spaces are restrictive for PWDs, especially in terms of sexual expression, and how technology could work around that. Through video chats and sharing of images, a subset of women with disabilities are able to engage in explorations of

sexual pleasure online, which might even have some advantages over in-person explorations in terms of safety: safety from STDs, protection of privacy, and (comparative) ease of access. However, the downside is that there is still limited privacy and safety for women with disabilities while using the internet because such realities are not generally not reflected in the movement. It becomes important then to see how addressing these concerns can include the needs and desires of WWD.

A space to explore one’s many identities

Persons with disabilities, especially visible disabilities, generally cannot compartmentalize their disability, to opt out of being identified with it. Often it happens that their disability eclipses all other facets of their personalities in the eyes of society. Walking around with disabled bodies, one experiences how “people stare but they don’t see; they look at the disabled body and can’t see the person.”⁴²

However, on the internet, things are different; one can choose which of one’s multiple identities to display or keep private. Our participants, especially those with visible disabilities such as those using assistive devices and equipment, commented that the Internet was the first avenue that gave them a choice to not share their disability status, ensuring that their disability identity is not the only lens they are seen through. For many, this act allowed them to explore other, less-visible aspects of their identity. Many of these experiences emphasized how this simple choice helped them escape the pitying that comes with the label of being disabled. These have provided some respite from the constant attention being given to their disability in the offline world.

Many shared examples of this experimentation:

“I do not think Facebook needs to be a true reflection...we do not want to advertise

42 Cohen-Rottenberg, R. (2017, September 28). Where Are All the Disabled People in the Body Positivity Campaigns? The Body is Not an Apology. <https://thebodyisnotanapology.com/magazine/where-are-all-the-disabled-people-in-the-body-positivity-campaigns/>

our disability there...we can limit what we share.Those who know (about my disability) know, those who don't know don't need to know."

For some WWDs, this has been an example of agency they were exercising online.

Participants also shared their choice to not share their disability status with everyone on Facebook, adding that they shared it on an individual basis when they felt ready. Upon knowing of their disability, people that WWDs had been talking to on Facebook either completely avoided them, or conversely, asked too many questions. Either way, the relationship changed.

"I do not have my disability status on Facebook. There are some people who stop talking to me when they find out that I am blind, and then there are some people that get hyper curious, and start talking even more."

These social experiments online have not only allowed our participants to slowly explore aspects of their identities, but also provided them with a window into how the world around them really thinks and feels about them.

One of our participants shared the example of her friend, who went from deliberately leaving out her identity as a PWD on Facebook, to then deliberately including it to stop being the target of unwanted attention.

"A good looking close friend of mine uploads her pictures in a way that the wheelchair is not visible. She was getting a lot of unwanted messenger calls from men, and was in a lot of stress. She was asking me for advice and I asked her to upload a full picture of herself. Once she uploaded that picture, those calls stopped. So we realized that these things (our disabilities) might not be talked about, but affect people."

This quote expresses how disabled bodies are discriminated against, and even when people are trying to project an image of being "tolerant" or "sensitive," their conventional

ideas of sexuality of WWD become visible in these encounters. While the participant was conventionally desired by a lot of men, the desire was contingent on assumptions of her able-bodiedness and collapsed with knowledge of her disability. Encountering conventional ideas of desirable bodies that do not have space for WWDs show how far we have to go in order for the sexuality of PWD to be acknowledged, let alone for disabled bodies to be objects of desire.

SRHR activists in our research also shared their experiences of going a step beyond receiving information on reproductive health to sharing it with others online, despite the risks it entailed.

"There was a post on "Period" and I shared it on Facebook because people say bad things to women which are negative and also a kind of domination towards women. It had appeared on my newsfeed. I keep sharing such posts."

Here, our discussant speaks of various ways in which she has been using her online presence when she shares such content. Her dedication to "keep sharing" these posts and keep engaging in these acts of resistance online is an expression of her agency, as well as an important contribution to ensuring alternative narratives are amplified.

However, safety on these platforms is not a given, and some of the paternalistic forces that are policing women's behavior offline also make their presence felt online. A few of the participants who were using online dating platforms shared their experiences, which were largely negative:

"This one time, [...] I was on my desktop and I got into those kinds of sites where I had to make my profile. [...] Then I started getting texts. I was totally surprised by why I was getting such texts. I looked at it but didn't reply. I got a message from this one person. He seemed genuine. We had a good conversation at the beginning. He said "Yes I know you've landed on this site without knowing about it. You are not that kind of person who lands into such places So, you just delete it and exit. I asked what

it is all about? He didn't explain much but yeah I remember happening such things to me landing into such unknown apps and space. Later on I deleted it hurriedly.

I can't say about others but in my experience it went very bad. After 6 months of my separation with my husband I tried to date online but my brother scolded me because of my previous experience. I also got scared. I don't feel safe dating online."

These two experiences show how the patriarchal policing of women's sexuality and sexuality of WWDs works in tandem online and offline, and often through one's own family. Our participant was judged because she was perceived as "not that kind of person" and asked to delete her profile whereas another was scolded by her brother until she was scared. Having a profile on online dating sites is another act that makes one seem "hypersexual", and women's admissions of their own sexuality through having a profile on dating sites, seemed to be too much for their own close ones to handle.

In the focus group discussions, participants agreed that online dating sites are not worth the risk – that it invites too much negative attention and judgment. They were of the opinion that sharing feelings with people through chatting options on other social sites (especially Facebook) was sufficient.

However, for a queer PWD who participated in the study, the experience is different -

"I identify myself as queer person[...], to find a partner I use dating apps but mostly dating apps in Nepal are used only used for sexual fun, if I want to have sex then I can open the app and find a partner..."

They also added,

"From dating apps, I can search partners according to my preference. We would talk like, talk secretly. Everything starts from online, and then goes offline. In queer community, everything starts from online."

Lack of safe spaces online



LACK OF SAFE SPACES ONLINE

Participant conversations pointed to a need for more safe spaces for WWD to have discussions on sexual expression. However, apart from their own Facebook pages, we did not hear any specific instances of safe spaces during these conversations with women with disabilities. In comparison, during the first phase of EROTICS survey among gay men and activist women, participants in those groups had shared the existence of secret groups that functioned as safe spaces.

As mentioned earlier, disability rights activists are creating safer experiences within their own Facebook circles by avoiding adding unknown people from outside the disability community. While the individuals are using agency to build a space that they desire within the community, this seclusion is also out of a necessity to prevent bullies and harassers. If not combined with other ways to communicate with the wider community, this strategy limits the conversations on sexual expression of women with disabilities to only their own circles.

Group discussants also spoke of an experience regarding YouTube, a platform that cannot be as carefully tailored:

“We had gone to watch a movie and the actors had met us, and put a video of that on Youtube. On that, they had interviewed us. I saw a lot of negative comments. We had said we liked the movie. There were comments like: now, blind people who are not able to see the movie are going to say it is good, perhaps deaf people will also say they like the movie without hearing it!!!

“There were a lot of disgusting comments.

“I think they [the moderators] deleted the comments later.”

This experience of getting harassed online as soon as one is exposed to a more mainstream audience helps us understand why women with

disabilities may choose to socialize online only in limited circles. Doing so can ensure that one's experience on the internet is largely positive and pleasurable. The stigma of being disabled and enjoying everyday activities leads to mocking on the internet –forcing many PWD to restrict sharing their experiences to an abled audience.

Online violence experienced by women with disabilities

Online harassment is generally understood as unwanted sexual conduct on digital platforms; Online violence includes harassment, threats or violence on somebody using technology or the internet. With this working definition, the label of harassment is applied to anything that is not welcomed by the recipient, regardless of the intention behind it. Our discussions of WWD's experiences on their own Facebook pages, as well as online dating sites and on Youtube have indicated the prevalence of intersectional violence they face, targeted for their identities as women and as PWD. Some of the violence is in the form of microaggressions, where persons with disabilities are given backhanded compliments, expressing admiration for being so beautiful or successful that they do not “seem disabled.” Other aggressions take the form of emotional labor, where WWDs are constantly asked by abled persons to answer their questions and satisfy their curiosities. In this section, we explore the intersectional violence faced online by WWDs, across the scale from micro to the macro.

Social ideas about what is acceptable and one's own socialization can affect how/when we feel harassed. Some of our respondents shared that sometimes the line between appreciation and harassment online is difficult for them to draw,

as seen in this participant's quote regarding comments on her Facebook posts:

“Mostly I get positive comments but some men comment “sexy body” — I don’t know if that is good or bad.”

The viewer's overt sexualization of one's body takes the appreciative remarks into risky “sexual” territory, creating discomfort and resulting in questioning whether one's reaction is disproportionate.

The sharing of pictures beyond the intended receiver was another problem mentioned during the discussions. As stated by the queer participant quoted in the previous chapter:

“In dating sites the pictures are posted to express sexuality so indirectly people comment with negative intention, and some people take a screenshot of my pictures and send it to other people.[.....] and the nudes that they share may be of the person might be of a different person.”

Another participant shared a similar experience of feeling harassed and taking steps to protect herself, even when she was not sure whether the behavior she received was harassment or not.

“Once, I went to a marriage ceremony in a sari. My younger brother took a picture of me showing my back, which I liked too, so I posted it on Facebook. The photo was not revealing too much skin, just a little bit of the back was not covered by the blouse. A boy commented on that photo “You are very sexy, I want to meet you.” I felt so bad because of that comment and I blocked him. I don’t even know him that well.”

Both these experiences show how caution and precaution are a big part of the online lives of WWDs, in order to both nip unwanted attention in the bud and also prevent the possibility of the conversation progressing into unwanted territory in the future.

Our discussion revealed a certain understanding among participants that harassment online is

also inevitable. There were some anecdotes shared of public persons who are harassed, who then accepted that harassment would be the price they would have to pay for their fame. For example, one participant shared:

“We have this person.... She is a dancer. Lots of her pictures are misused too. There are fake pages using her pictures as well. I informed her about it and told her to report but she didn’t pay much attention thinking it comes along with the popularity. But personally, I don’t think it’s right. Maybe she thought it was right and didn’t take any action. So the photos are misused the most.”

Our participants were also of the opinion that the experience of harassment is felt by women more strongly because of their painful awareness of their own vulnerability and that having disabilities compounds this.

“Yeah there are a lot of cases that happen in the community like being asked to meet and falling victim to a rape attempt, based on the fact that disabled people cannot stand for their own help.”

“What happens to us mostly is, among amputees, is that people first try to emotionally blackmail us. They know about our bodies and the level of injuries, and comment accordingly. For example I have injuries all throughout. It’s clearly seen when I am wearing stockings. They used to ask for pictures of my stump. I did not realize at first. People ask for pictures of stumps the most. When we take pictures of stumps there are chances of our private parts being captured in the photos. Nepali boys aren’t that much forward so they don’t bother to ask for sure. But people from foreign countries ask for [photos of the stump] the most.”

These experiences point to the multiple levels in which WWDs face harassment online. One is the limitations imposed by a disabled body, and the vulnerabilities it creates – where mounting an effective self-defense in case of attack might be very difficult.

Online harassment of WWDs deserves separate examination because the type of harassment used to target them and their own experiences of being harassed may be different from other demographics. In addition, subtle tactics such as harassers online asking someone for a picture of their disability just to ogle at their private parts shows how alert WWDs have to be, even when engaged in routine behaviours online that would seem to be low-risk. Encouragingly, the example also shows a high level of awareness of these threats, and active self-protection taken to avoid these risks online.

Then there are instances of randomly being added to sex groups on Facebook, being solicited for sex online, and receiving sexual messages, which has created additional problems for those with visual disabilities who were on the receiving end of sexual photos but did not know what they were receiving.

In addition, two participants in this research have also experienced being a victim of cybercrime, with their IDs being hacked, receiving unwanted photos and videos, and having their photos or videos publicized without consent.

To close this section we go to a story shared by one of our interviewees:

“Another experience was, once a person sent me a friend request on Facebook. He sent me a message which I didn’t respond to. My brother also uses my phone and my brother replied to him saying “Hi, how are you?” The message was from a foreigner... I don’t remember his name now, I think his name was Richard or something. I knew that was a fake id. He found my number, I don’t know from where but he called me by using another girl. She said that you have a parcel from Richard, UK so come to the airport with \$400. I had just started to work and at that time I didn’t have that much money. Even if I had that money I wasn’t going to give it to them. And then I said nobody is there in the UK to send me a parcel so do not call me otherwise I will

go to the police.

“Then that person started to blackmail me by saying he will send my pictures to my friends and family. The photo was not mine, it was photoshopped with my face and someone else’s naked body. I was so stressed, I was in my office and I talked to my brother, and he suggested that I go to the police and report the case. I did that; I went to the police station in Teku, filed a cyber crime report showing the pictures and that fake Facebook ID. The facebook ID was subsequently blocked but the number that called me could not be traced - they said the call was from India, but the girl was speaking Nepali. This case happened about 2 years ago.

“I didn’t tell anyone except my older brother. I didn’t even tell my mother because she will judge me and my character. If I tell my friends, they may think that I sent him those kinds of pictures. It is very awkward to talk with friend about sex and sexuality in the context of Nepal. I can’t talk with anyone. Only with your husband or your sexual partner can you talk [about it] or with the people who know a little bit about the topic. In my case, I can’t talk with my husband either. I used to frequently watch porn with my husband. Actually, he taught me to watch porn. But when we divorced, he blamed me, saying that I am a characterless girl who watches porn.”

In this story we can see a perfect storm where online harassment, the technological aspect of the crime (modifying and superimposing images), fraud, impersonation, moralistic attitudes towards women’s sexuality and the sexuality of women with disabilities all come together.

While this snapshot provides us with a bleak look into all the challenges that women with disabilities have to face today in the online world, we end our analysis on a hopeful note in the next section.

Life without the internet will be dull

For a final word on the Internet, we present this snippet from an activist who is based at home:

“I am disabled and my family and friends don’t allow me to go out of my house as they want to keep me ‘safe’ from outside or they don’t want me to work. I can’t imagine my life without the internet. My life will be dull.”

Connections and mobility via the internet has been beneficial for PWDs. The barriers to access, and the exclusion and the violence prevalent in offline spaces need further exploration to make the internet a space where women with disabilities can thrive.



**Recommendations
for a dignified life
online**

RECOMMENDATIONS FOR A DIGNIFIED LIFE ONLINE

One of our participants shared how the Internet could be a positive asset in helping improve the lives of women with disabilities:

“For a person with a disability to live a dignified and normal life, everything, such as – education, employment, relationship, children etc. is needed. And, social media and the internet should make it seem like a normal thing. The Internet should make the abled people feel that it’s normal for PWD to live a life like abled people. If a wheelchair woman marries and has children, people think like – “Does she need a marriage? Does she need children?” And, if a blind girl marries and gives birth to the children, people say the things like – why do they have to give birth to children even when they are blind etc. People react strangely and awkwardly. So, I hope after ten years, we would see some changes. I hope abled people would feel totally normal about PWD getting married, having children etc. And, I think that the internet and social media should help us in this regard.”

Based on our research, these recommendations are in the interest of promoting freedom of sexual expression for women and queer people with disabilities online:

Recommendations for the government and its institutions

The national policies infringe on freedom of expression and often criminalise sexual expression, limiting and controlling how people express their opinions and desires. The Electronic Transaction Act⁴³ and Information Technology Bill⁴⁴ restricts one’s sexual expression online. Besides the national regulations and laws, there is moral policing from the local governments on citizens, especially on women and girls. Similarly, national policies that are unfriendly to PWDs by being ableist and heteronormative in their design, including the Chapter on Family Law in Civil Code (Muluki Aparadh Ain) 2017 and Privacy Act 2019 puts women with disabilities at further risk of marginalisation⁴⁵. These laws and regulations that restrict freedom of expression and sexual expression of citizens, and curb PWDs from enjoying their human rights require amendment.

Many PWDs rely on online spaces and digital technology to access information, services and community that are otherwise inaccessible to them. However the cost of devices and internet connectivity is still high and there are only limited concessions from the state. The current provisions from the government, with subsidies on using the internet for those with hearing impairments is commendable. However this framework could be expanded. The PWD community will benefit from affordable devices

43 Dahal.T. et. al.(2016) Freedom of Expression on Internet in Nepal. Freedom Forum. https://ifex.org/images/nepal/2016/08/05/nepal_freedom_expression_internet_freedomforum.pdf

44 (2019). Policy Paper: Information Technology Bill 2019, from a feminist lens. Body and Data. <https://files.bodyanddata.org/nextcloud/index.php/s/WCRo3DL6XcBGLij>

45 The Privacy Act 2018. s. 6 (Nep).

Section 6 of the Privacy Act mentions that if someone is of ‘unsound mind’, the matter relating to reproductive health and pregnancy of can be provided to the member of his or her undivided family and for his or her guardian. This is direct violation of right to privacy of individual and does not respect autonomy of individual to understand their bodies and make decision about it, so should be amended. The term ‘unsound mind’ itself is ableist and could be interpreted to further marginalize women with intellectual and psycho-social disabilities.

and discounted internet plans. PWDs should not be only seen as beneficiaries to these services but also key stakeholders in consultations to develop national policies around ICT and strategies.

Recommendations for the disability community

The way that needs of PWD are identified is not inclusive of people from different walks of life, and is mostly led by Brahmin cisgender heterosexual individuals. This results in a hierarchy of needs where aspects of sexuality are not considered as 'basic needs', thus excluding the voice of many in the community. The agenda setting of disability rights movement needs to be inclusive of women and queer people with disability across caste, ethnicity, class, education, geographical location, and age. Persons with severe disability tend to be excluded from disability rights discourse; greater effort must be applied to include them as well. Narratives around what are seen as 'good' or 'bad' use of the internet and online spaces need to be restructured to hold the nuances and messiness of one's expression in online spaces. The risk to just one person speaking up on issues of sexuality can be overcome by a concerted campaign where everyone participates, thus bringing attention to the problem, while distributing the risk and ensuring that the negative attention can be dealt with as a community, rather than individually.

The self-censorship among activists with disabilities due to the pressure to perform as a role model to the community needs reassessment; their individual right to freedom of expression needs to be addressed. Sexuality of women and queer people with disabilities should be acknowledged as a priority of the movement, so they feel accepted fully, besides just their 'activist side'.

While the community does support each other when harassed, they do not have any forum for ongoing discussions on issues of disability and sexuality, and in the lack of such a safe space, they are limited to having these discussions only when they are invited to international forums.

Recommendations for technologists and developers

Access to technology and the internet is key and a first step for someone to be able to express themselves freely and openly. However, digital technologies are often not friendly to PWDs in their functions and/or interface and access to these technologies to PWDs comes as an afterthought. Not all social media platforms and their content are accessible to PWD. Even the technology projects developed to assist PWDs usually collect suggestions and feedback once they are ready (rather than seeking during earlier design stages). PWDs are also often expected to provide this constructive review and feedback without any compensation. To make digital technology accessible to PWDs whether it is directly catered to them or not, there must be meaningful participation and consultation with the community from inception of the project until its execution. Such a practice of seeking suggestions from the community regularly will only improve the quality and inclusivity of the product.

Recommendations for the wider community

Society at large needs to bear accountability for how conversations about disability and sexuality take place. Looking at women and queer people with disabilities beyond the objects of pity and needing support, society needs to make their stories of resistance more visible, and respect their agency. Conversations around disability and sexuality can broaden the range of futures that a woman with disability is able to imagine for herself, whether that future includes marriage, a family, and sexual pleasure, or not. Safe and open spaces must be created where these conversations can take place free of judgment. There is also an urgent need for more academic research into the disability community in Nepal, with a focus on women and queer persons within the community. Existing research as well as new knowledge production on this should be widely distributed in accessible formats.

Recommendations for other movements

For intersectional movement building, the queer rights movement, the women rights movement and sexual rights initiatives need to intersect disability in their work and activities. As our research shows, even among activists, open conversations on sexuality do not happen. Mainstream judgments continue to view sexual expressions of women as unacceptable. Ideas of sexuality are still narrow, and limit discussion. Initiatives that expand the definition and understanding of sexuality in Nepal are necessary. Addressing issues of online privacy, consent and security within the discourse of sexuality is equally important. Participants' understanding of privacy, consent and data protection is low, with self reported instances of activists violating the right to privacy of others by posting things without their consent. It is important that activist women with disabilities be supported with training to understand these concepts and apply them within their communities.

APPENDIX

FGD guiding questions

1. Can you introduce yourselves?
2. Do you use multimedia phones? And do you have internet on it? Do you have internet facility where you live?
3. Have you been using any government facility in terms of using internet and other services?
4. Do you use any specific apps in relation to your disability? (apps for visually impaired people) Do you find it easy to use?
5. Do you use social media channel (Facebook / Twitter/ Insta or others? Any difference in using certain social media for certain purpose? What do you use most/? What do you prefer using?
6. How much of information you share about yourselves in those platforms (photos, feelings and emotions/information, etc.)?
7. What kind of comments or reaction do you get in social media on your posts and how do you react about it?
8. What kind of content in social media do you consider are related to sexuality? Do you post such content?
9. Have you ever faced any kind of abusive comments expression related to your sexuality? Do you get comments related to your disability)?
10. Have you heard of dating apps? Do you or your peers use them? What has been your experience?
11. How do you see role of internet to explore and express sexuality?
12. Do you use any platforms to express your sexuality and for pleasure (watching porn/ making tactic/watching tiktok)?
13. Do you engages in conversation about bodies and sexuality online? How?
14. What kind of bodies do you see being represented online? What kinds of conversations do you see happening online about bodies? What do you think about them?
15. Do you think in people are bias or are abusive towards the PWD in the internet? What kind of biasness you have faced/seen?
16. Do you censor yourself because of possible threats, negative comments and violence online?
17. Have you used any measures to counter the abusive comments and violence online? (argue with the people online, report the post or comments, delete, report to police, etc.)
18. Has internet help you to find support through friends, networks, and website?

Interview schedule

Beyond Access: Women and queer persons with disabilities expressing self and exploring sexuality online

General Information

Name

Age

Caste

Ethnicity

Occupation

Gender/ sexual orientation

Marital status

Accessibility

1. Do you use internet or not? If yes, where do you use internet and in what device?
2. How supportive these devices and the internet platforms are to navigate your day-to-day lives?
3. What are online platforms and applications you mostly use? Are there any access issues?
4. What are the challenges using these platforms? Do you use any specific apps or program based on your disability needs?
5. Are you benefiting from any government policy and plans in relation to telephone or internet access and use?
6. Has anybody (policy makers or technology companies) come to you to discuss/ consult about your need and experiences in terms of internet/technology and accessibility?

Expression/platforms and experience

- How often do you share your personal information (photos, opinions) online?
- What kind of platforms do you use to share your thoughts? What kind of platforms do you use to express your sexuality?
- What kind of platforms/ websites do you use for information collection related to sexual health and sexuality?
- What kind of bodies do you mostly see in the internet? How are disabled bodies shown and perceived?

Experience online

1. Have you faced any online abuses and appreciation? What was your experience?
2. Have you seen any kind of online abuse being faced by peers from disability

community?

3. Have you faced any online abuse or appreciation because of your expression related to your sexuality? Share any experience.
4. What kind of comments do you get when you post certain kind of (feeling, thought, photos, etc) content?
5. Do you censor yourself because of possible threats and violence online?
6. What kind of measures do you apply to counter violence you face online? (Argue with the people online, report the post or comments, delete, report to police, etc.)

Sexual expression in online platforms

1. Nepal government has banned pornography saying that it is source of violence on women and children, what do you think about it?
2. Do you use any platforms to express your sexuality and for pleasure (watching porn/ making tiktok/watching tiktok, using dating apps)?
3. If you have an intimate partner, how do they react to your expression online, like when you share photo online? Would it be different if you were a single person?

Movement building/Community building

1. How has the internet been useful for movement building, has it contributed to Nepal's disability movement?

**Beyond Access:
Women and queer persons with disabilities
expressing self and exploring sexuality online**



**Body & Data is a digital rights organization in Nepal that
aims to increase women and queer persons' engagement in
digital spaces through suitable strategies for
expression, autonomy and agency.**

bodyanddata.org