

DISABILITY AND SEXUAL AND REPRODUCTIVE HEALTH RIGHTS (SRHR)

A Study on

Barriers in accessing sexual and reproductive health services among adolescent girls and young women with visual impairments

2021

**Study Commissioned by
Prayatna Nepal and Mama Cash, the Netherlands**

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Dedicated to all the research participants who voluntarily participated in the study. Thank you for sharing your journey with us!!

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DISCLAIMER

Prayatna Nepal and Mama Cash, the Netherlands, commissioned "Barriers in Accessing Sexual and Reproductive Health Services among Adolescent Girls and Young Women with Visual Impairments". The opinions expressed in the report are those of the researchers and do not necessarily reflect the views of Prayatna Nepal and Mama Cash, Netherlands

EXECUTIVE SUMMARY

1. INTRODUCTION

Prayatna Nepal (<https://prayatnanepal.org>), with the grant support of Mama Cash, the Netherlands (www.mamacash.org) commissioned this study that aims to explore the barriers in access to Sexual and Reproductive Health (SRH) Services of adolescent girls and young women with disability, particularly, of those with visual impairments. When it comes to accessing essential health care services, girls and women with disabilities face numerous obstacles. As a result, they have not only faced numerous challenges to maintain personal health and hygiene but also have been forced to compromise their fundamental human rights, such as Sexual and Reproductive Health (SRHR), which is an overarching construct. Within the broad spectrum of SRHR; this study focuses on the SRH ‘services’, addressing the ‘access’ aspect of it, from the perspective of the service recipients or the users of the services [Research participants: Girls and women with visual impairments which include blind, partially sighted and low vision]

Adolescent girls and young women with visual impairments are facing a myriad of challenges while accessing essential health care services in their respective communities across the country. The situation is more poignant in rural communities and in those who have multiple disabilities. Nepal has ratified international conventions and made national provisions, upon realizing the concerns and issues of people with disabilities, including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2010. Nepal’s Constitution (2015) ensures the rights of persons with disabilities with dignity, equality, and respect. The Constitution has also guaranteed health as a fundamental right of every citizen of the country. However, the patriarchal social order and deeply rooted discriminatory social norms and values continue to sustain gender-based violence, harmful practices, and discrimination that permeate into all aspects of women’s public and private lives affecting bodily autonomy and right to self-determination, which includes equitable access to SRHR services. However, research findings, anecdotal evidence, and experiences of persons with disabilities, disability right activists, and SRH right advocates indicate that girls and women with disabilities experience discrimination in realizing their SRHR (CREA, 2012) and they are often invisible, unreported, and marginalized within the sexual rights discourse in Nepal (Kayastha, 2016) for several reasons ranging from structural to social.

In addition to stigmas against disability and sexuality, stereotypical views of these issues are significant barriers to accessing SRHR services. This includes the perception of girls and women with disabilities as ‘Asexual beings’; not capable of motherhood and thus, not recognizing SRHR as their basic needs. They are subjected to harmful practices like forced sterilization; use of medication to suppress sexual desires, and Eugenics (Open Society Foundations, 2011). Research on reproductive health largely ignores women with disabilities and the nature of such

discrimination and what works to ensure access to services for them. (Morrison et al., 2014; Hameed et al., 2020).

2. RESEARCH FRAMEWORK; METHODOLOGY AND SCOPE

This study explores the ‘lived’ experiences of 12 adolescent girls and young women with visual impairments (blind; partially sighted; low vision) aged between 18-30 years; adopting qualitative research methodologies. The study draws upon World Health Organization (WHO)’s AAAQ framework on ACCESS to health care services (WHO, 2016; Unicef, 2019). The framework states that for the health services to be accessible, they must be continuously available and in sufficient quantity (**Availability**); physically accessible and financially affordable (**Accessibility**); ethically and culturally appropriate for all, and especially sensitive to vulnerable groups (**Acceptability**) and comply with applicable quality standards (**Quality**). Disability rights activists argue that there has been an expansion of SRH services in recent years with efforts to improve the quality and availability of services including availability of information in accessible formats (braille; audio; sign language). This is expected to improve access to SRH services (at least in the urban areas). However, the access is reported to be substantially low even in cities with a wide network of services and even among well-informed service users. Therefore, this study aims to explore what (and how) ‘still’ inhibits the girls and women with disabilities to access the SRH where measures to address the identified barriers such as those related to accessibility, affordability, and quality have been addressed. Hence, the study explores access to SRH services from the perspective of service ACCEPTABILITY with focus on the following **RESEARCH QUESTIONS**:

1. *Even ‘When’ or ‘IF’ the barriers relating to Availability, Accessibility and Quality are addressed, what can still hinder ‘access to services’?*
2. *What is the nature of these barriers?*

The overall objective of the study is to: *Explore the barriers faced by adolescent girls and young women with visual impairments (blind, partially sighted, low vision) in accessing SRH services with the following specific objectives*

Specific objective 1: To explore the adolescent girls and young women with visual impairments’ understanding and orientation towards SRH needs and services

Specific objective 2: To explore the adolescent girls and young women with visual impairments’ experiences of accessing SRH services

Thus, the study examines the acceptance of the SRHR among visually impaired girls and women, i.e. participants' willingness to benefit from the SRH services. This was carried out by exploring the construct of “disability-friendly SRH services” as experienced, understood, and expected by the participants themselves to understand how constraints (problems/challenges) unfold while realizing disability-friendly SRH services. ACCEPTABILITY encompasses both dependent and independent variables (DIHR, 2017), including the physical environment (equipment, space), as well as an enabling environment (privacy and confidentiality), which are not part of acceptability definitions yet can negatively and positively affect it. (Bucyibaruta et al., 2019). Independent variables include demographic and socio-economic features--age, gender, marital status, education level, poverty and are likely to include disability. Thus, this study explores "if" and "how", and "disability" plays into the acceptability of the service. In addition, it describes the conditions of

discrimination in the provision of SRH services that are based on disability. The study, therefore, explores how gender, disability, and SRHR interact to create unique barriers to access to SRH services for girls and women with disabilities, in general, and for girls and women with visual impairments in particular. The study does acknowledge the importance of an intersectional perspective in understanding access to services, however, the intersectional discrimination and marginalization as it pertains to social identities, including sexual and gender identities (SOGI), have not been explored. The participants were not asked to provide their SOGI or other social identities, nor were any inquiries made about it.

Key findings

This study found that girls and women with disabilities face barriers in accessing SRH services. In addition to physical and structural challenges, the 'ACCEPTABILITY' of the service is identified as the major challenge, which is influenced by how girls and women with disabilities interact with the community and with service providers.¹

Users-Community Interaction: Orientation towards SRHR services

In most cases, girls and women with visual impairments begin to develop an understanding of SRHR much later in their lives, often after their teen years, mainly through SRHR trainings. Early introduction to sexual and reproductive health through family and other members (including formal school education) tends to be limited (in relation to contraception; menstrual hygiene) and restrictive (discouraging discussion of sex and sexuality). It is the narrative that "Sex is shameful" and the practices that perpetuate it through secrecy and embarrassment that instill feelings of shame and discomfort. The early memories of menstruation are described as traumatic not because they cause physical pain, but because they come at the beginning of a period of difficulty, as well as the associated fears (such as anticipated restrictions in movement, isolation, social ostracisation). Furthermore, the narratives about sexual violence against girls and women with disabilities referring to their '(in) ability' to protect themselves as the result of their 'disability' (and their own experience of violation), further reinforces their fear. Some participants have been exposed to SRHR trainings/orientations that are able to conceptualize and define SRHR and in much broader terms; acknowledge that sexual desires are natural for all and it doesn't matter if they have a disability or not, and have also expressed their curiosity and interest in exploring this issue.

Furthermore, they emphasize the importance of open dialogue on the issue, but at the same time describe SRHR as a "different thing" [not usual] and express their hesitation and discomfort with the topic. There is a perception that even close friends do not speak openly; often because of shame and fear of being judged as "characterless" thus choose other ways to safer ways such as forceful sterilization; removal of the uterus without thinking deeply about SRHR and dignity of person with disability. Because of the stigma surrounding SRHR and the culture of silence, the participants' perception and priority for the needs of SRHR are affected. There is an interplay between the social narratives that problematize sexual and reproductive health care; the participants' fear of judgment and their need to uphold social values and norms (around sex and

¹ As defined by Gilson acceptability of services include three aspects: interaction with community (User-community interaction); interaction with the health care professionals [User- provider interaction] and interaction with the health institutions (User-institution) [Gilson 2019 as cited in Bucyibaruta et al (2019)]

marriage); attached apprehension and trepidation of possible violence as well as the PROTECTIONIST approach when it comes to girls and women with disabilities, which leads to a situation where their SRHR needs are not considered usual (as other health needs); and something that needs to be handled in private. Even though girls and women with disabilities may be aware of their rights and 'know' about SRHR services, family members as 'gate keepers' play a key role in deciding and prioritizing needs, denying them their agency. Even in situations where participants are able to decide for themselves, the need for a companion compromises their autonomy and right to self-determination.

Users-Provider Interaction: Experience in accessing SRH services

Because of stigmatization and lack of informed choice, SRH services are not openly solicited and are not sought to ensure privacy and confidentiality. Evidence has clearly highlighted that in the participants' experience with healthcare providers, their expectations are not met. On the contrary, the healthcare providers' conducts reinforce their fear and apprehension, that further strengthened their conviction that the service providers cannot be trusted, and hence are discouraged for accessing the services.

While two of the participants said their experiences at the health service facilities were good, the rest felt that they were treated differently since they were disabled. They shared that they have been mocked regarding sex and marriage ('pre-marital sex') and treated in a demeaning manner. Comments have been made emphasizing the notion that a person with disabilities 'cannot bear' or 'should not bear children, including suggestions for abortion (and avoiding pregnancy). They are discouraged from seeking the services, with the suggestion that they do not 'need' the services. Moreover, participants have been violated during check-ups, ranging from verbal comments on bodies (with regard to disability and beauty) to inappropriate touching. Apparently, the service providers took advantage of the 'situation' in which they are seen as disempowered and vulnerable because of their disability.

In accessing SRH services, the conduct of the service providers is identified as the most problematic aspect, since they not only uphold social norms but also act as gatekeepers, enforcing moral standards. Furthermore, guided by their deeply ingrained prejudice against girls and women with disabilities, they apply the general notion that "girls and women with disabilities are not capable of engaging in sex or reproduction and do not need SRH services" which leads to girls and women with disabilities not being considered eligible and thus not entitled to SRH services. In the delivery of services, these prejudices manifest themselves as abuse and discrimination.

Consequently, deep-rooted socio-cultural norms and beliefs about sexual and reproductive behaviors (regulated via the institution of marriage) and the added value judgment towards the girls and women with disabilities, particularly applied by the service providers; the violation of privacy and bodily integrity (abuse), dehumanizes women with a 'disabled' body and effectively disenfranchises girls and women with disabilities from SRH services. In this way, girls and women with disabilities face unique barriers to accessing SRH services.

Service Acceptability: Expectations with disability-friendly SRH services and their barriers

Girls and women with disabilities are apprehensive in accessing the available services for fear of disclosure, fear of being humiliated, and fear of being abused. Hence, they prioritize three elements that define their acceptability of the SRH services i.e.: Confidentiality, Dignity, and Safety. Hence, for an ‘acceptable’ disability-friendly SRH services, girls and women with disabilities expect to access full privacy and confidentiality; judgment-free service with recognition dignity by accepting them as rightful clients and providing them a safe environment. The healthcare service providers need to ensure these key elements of ‘disability-friendly SRH services’ in their service delivery for which “trust” is the key factor, lack of which contributes towards girls and women with disabilities unwillingness and hence barriers to accessing SRHR services. This focus is also important for the human rights-based approach, which calls for recognition of the user’s rights and sense of entitlement to the services as emphasized by ICPD, which recognizes that people’s sexual and reproductive health needs are rights that they are entitled to demand. The Privacy Act (2018) of Nepal also has provisions to ensure the right to privacy in matters relating to the body.

3. CONCLUSION

The study has shown that girls and women with disabilities, like all other girls and women, face barriers to accessing SRH services, however, those barriers are compounded because females with disabilities face added vulnerabilities. The combination of gender-prescribed roles and disabilities creates a particular set of barriers for girls and women with disabilities. In addition to gender and other forms of social marginalization and exclusion, it is imperative to include disability as a dimension of exclusion for accessing SRH services. Physical accessibility and financial affordability are essential, but ‘Acceptability’ of services is equally important and indeed even more critical in the case of girls and women with disabilities, which is necessitated by disability-friendly SRHR services. The relationships between women and girls with disabilities and the larger community as well as their interactions with healthcare providers, which in turn shape their expectations and acceptance of disability-friendly sexual and reproductive health services, shape SRHR. Lastly, confidentiality, dignity, and safety make services acceptable to girls and women with disabilities. Thus, SRH services should take into account and recognize the issue of dignity and safety in order to ensure an equitable access for girls and women with disabilities.

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LIST OF ABBREVIATION

AAAQ	Accessibility; Availability; Acceptability and Quality
HRBA	Human Rights Based Approach
ICPD	International Conference on Population and Development
ICT	Information and communication technology
IPPF	International Planned Parenthood Federation
LGBTIQA+	Lesbian, gay, bisexual, transgender, gender diverse, intersex, queer, asexual and questioning
OPDs	organization of person with disabilities
SOGI	Sexual Orientation and Gender Identities
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health and Rights
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization
YRS	Years

- The lack of access to education, essential health care service, and facility as well as employment opportunity, along with weak social security system make persons with disabilities more likely to live in poverty.
- Unemployment and underpayment are more common among people with disabilities. Evidence has highlighted that women with disabilities are less likely to be employed than men counterparts.
- Persons with disabilities are less likely to access formal education and higher-level education. In Nepal, 8% have no education (77.7% of females) while 30% are deprived of any kind of treatment.
- People with disabilities face higher risks during disasters and emergencies. The Covid 19 pandemic has caused income losses and food insecurity, among other challenges for many—people with disabilities.

[The IDS (2020); Norad (2012)]

1. Introduction

Prayatna Nepal (<https://prayatnanepal.org>), with the grant support of Mama Cash, the Netherlands (www.mamacash.org) commissioned this study that aims to explore the barriers in access to Sexual and Reproductive Health (SRH) Services of adolescent girls and young women with disability, particularly, of those with visual impairments (www.mamacash.org). The primary objective of this study is to explore the barriers to accessing Sexual and Reproductive Health right and services (SRHR) for girls and women with visual impairments particularly in the study area and generally in Nepal.

Following the preliminary consultations with organizations and individuals working extensively on SRHR sector in Nepal (7 individuals/3 organisations including Prayatna Nepal), a common consensus was developing to focus the study only on one type of disability [adolescent girls and young women with visual impairments i.e. blind, low vision and partially sighted; aged 18 to 30 years)]. The agreement created by a research team and organizations and individuals

helped to make the study more precise and practical. However, the findings of this study would be more relevant to the specific target group (i.e. girls and women with visual impairments) for programmatic inputs and advocacy purpose.

This study is based on the ‘lived’ experiences of girls and women with visual impairments in accessing SRH services. Thus, it has explored and explained context and category specific experiences and constraints. Therefore, the study attempts to show how gender, disability, and SRHR interrelate in terms of the unique barriers it creates for girls and women with disabilities in general, as well as girls and women with visual impairments in particular.

[Note: throughout this report the term ‘visually impaired girls and women’ or girls and women with visual impairments is used to refer to adolescent girls and young women (aged 18-30) who are blind or partially sighted or with low vision]

2. The context of the study

The population of Nepal is 28.9 million [54.19% female and 22% adolescent (10-19 yrs.)]², making it a symbolically diverse and culturally rich country. However, Nepal is also heavily stratified socially, where people with certain social identities face greater degree of discrimination based on their caste, class (economic and social), religion, gender, and physical conditions—disabilities (Bhattachan et al., 2009; Bennett, 2006).

² 16-40 years age group is considered as the youth population in Nepal, which is said to be 40.3% (45.8% male; 54.5% females) as per census 2011.

The national population census (2011) has shown that disability prevalence rate is 1.94% with 45% female. The disability movement in Nepal, which claims it to be much higher, contests these figures [aligned with a global prevalence rate of 15% (WHO, 2011)]. The potential reasons for the significant gap between the global average and Nepal could be the entrenched stigma against disability in Nepal, which has led to no or underreporting of disability during the time of the national census. The lack of well-trained researchers to collect information on stigmatized issues such as disability is an equally responsible factor. The prevalence rate of persons with visual impairments is reported to be 18.5% (Census 2011).

Nepal has ratified the UNCRPD in 2010 and the country's constitution (2015) ensures the rights of persons with disabilities. Several policies and legal frameworks have been endorsed to ensure the rights of persons with disabilities such as the Act on the Rights of Persons with Disabilities (2017). In practice, however, persons with disabilities continue to face social discrimination and additional challenges because of culturally and religiously embedded beliefs such as the belief that the disability is the result of a past life sin. (Holmes et al., 2018). In the case of women and/or belonging to marginalized castes, class or ethnic groups, or rural areas³, they often face multiple and intersecting discriminations which intensifies their vulnerabilities to create a unique set of disadvantages on many fronts—women, disability, caste, and ethnicity, belong to rural communities. However, limited evidence has highlighted that such intersections of exclusion based upon social identities and disabilities have been relatively understudied (NIDA, NIDWAN & AIPP, 2018). Moreover, the wider discourse on social inclusion and other social movements for rights, equality, and justice in Nepal such as the indigenous movement, Dalit movement, youth movement, and LGBTIQ+ movements are not disability-inclusive which means limited spaces for women with disabilities to raise the issue of multiple and intersectional discrimination and marginalization (Kayastha, 2016).

Patriarchal social values and deeply rooted discriminatory social norms practices continue to sustain gender-based violence, harmful practices and discrimination that permeate into all aspects of women's public and private lives affecting bodily autonomy and right to self-determination, which includes equitable access to SRHR services (OHCHR, n.d.). SRHR has been recognized as a fundamental human right and determining factor in health and well-being. It is also considered critical for gender equality, justice and sustainable development and is embraced in several international, regional and national legal frameworks, standards and agreements. The UNCRPD (Article 25) guarantees the right of full enjoyment of the highest attainable standard of health and sexual and reproductive health rights without discrimination based on disabilities and mandates the state parties to ensure inclusive health. Nepal's Constitution (2015) has established the reproductive and sexual health

- Girls aged 15-24 are significantly less likely to be literate than their male peers
 - Legal age of marriage is 20 yrs. in Nepal. Yet 28% of girls aged 15 to 19 years are married (Amin et al).
 - While contraception is available in 95% of all health facilities, only 23% of girls aged 15-19 yrs. use it
 - Only 40% of girls and young women aged 15 – 24 yrs. knows that abortion is legal [up to 12 weeks on demand under all circumstances and later in special circumstances]
- (Source: Presler-Marshall, 2017)

³Includes marginalized and vulnerable groups such as poor, Dalits- religiously classified as lower caste group and hence untouchable; Madeshi communities in terai (plains) facing racial discrimination; religious minorities (Muslim, Christian) and those from rural hilly communities. Marginalized group also includes people with different sexual orientation and gender identities (SOGI)

rights of women as fundamental rights under right to health, rights of women and rights to social justice. Furthermore, following the principle of Constitution of Nepal (2015), the Act Relating to Rights of Persons with Disabilities, 2074 (2017), enacted to ensure the constitutional rights of persons with disabilities, includes a separate section on additional rights of women with disabilities and includes provisions for the protection of their health and the reproductive right (section 19).

Globally, the Sustainable Development Goals (SDGs) builds upon the main principle of ‘leave no one behind’; which means the most excluded groups must get the highest priority, which includes men and women with disabilities. SRHR is recognized as an integral part of girls’ and women’s rights to be free from discrimination, coercion and violence, and enshrines the principles of bodily integrity, dignity, equality, and respect for diversity (High-level task force for ICPD, 2013). The SDG’s goal also encompasses many key aspects of SRHR, including access to SRH services, comprehensive sexuality education and the ability to make decisions about one’s own health. SGD's Goal 3 mentions, "Ensure healthy lives and promotes wellbeing for all at all ages" and Goal 5 highlights, "Achieve gender equality and empower all women and girls", including specific references to universal access to sexual and reproductive healthcare services (as agreed in ICPD). It includes services for family planning, information and education; reduction of maternal mortality rates and goal; elimination for all harmful practices, such as child, early and forced marriage and female genital mutilation and the integration of reproductive health into national strategies and programs (Guttmacher Institute, 2015; IPPF Africa Region, nd). Nepal is a signatory to the International Conference on Population and Development Programme of Action (ICPD-POA), thus, the government has official obligations to ensure the rights and dignity of marginalized and vulnerable groups including girls and women with disabilities living across the country. Aligned with the national constitution, the national health policy (2014) recognizes reproductive and sexual health services as basic health rights and incorporation health services of persons with disabilities into basic health. Though the right to health for persons with disabilities and reproductive health rights are covered, important legal and policy frameworks, which include the national constitution (2015) and the national health policy (2014), are silent on the sexual and reproductive health rights of women with disabilities specifically (Adhikari, 2019). The recently enacted ‘Safe Motherhood and Reproductive Health Rights Act (2018)’, recognizes ‘SRHR including safe abortion’ as a fundamental human right and includes specific provisions for mainstreaming adolescents and disabilities in all aspects of the services, without discrimination based on caste, age, marital status or disability. Besides these national commitments and policy frameworks, the National Reproductive Health Strategy 1995, the Adolescent Health and Development Strategy (2000), the National Safe Motherhood Plan 2002 - 2017, and the Nepal Health Sector Program II (NHSP II, 2010-2014) incorporated broad strategies for reproductive health which, however, are mainstreamed disability beyond measures for prevention of disability through immunization and other interventions in maternal health (WwD Network, 2018). Therefore, women and girls are yet to fully realize their SRHR. This situation is even more challenging for unmarried girls and women with disabilities as sex is viewed as being legitimate only when it is between two individuals within the ambit of a heterosexual marriage setup (Tripathi, 2020). The general notion that renders sex, sexuality, and sexual rights of young and unmarried people as “problematic” as it is deemed to deviate from the ethical, moral codes of the society and thus efforts to control and regulate their sexuality, though stick gender norms and use of social institution of ‘marriage’ to sanction women’s sexuality and freedom and the subsequent stigmatization of unmarried adolescent’s sexuality translates into barriers to reproductive health, particularly for adolescent girls (Shrestha & Wærdahl, 2020; Tripathi, 2020). SRHR services are

deemed unnecessary for young/adolescent and unmarried girls. In spite of such restrictive social attitudes and norms, studies have indicated that marital status does not always dictate a girl's choices (CREHPA, 2002) whereas, young girls are also highly vulnerable due to early marriage and early childbearing including repeated pregnancy and forced abortion due to son preference. (UNFPA, 2017; The New Humanitarian, 2014). This emphasizes the importance of SRHR for all girls and women irrespective of their marital status or age (adolescent) or disability. On the other hand, studies, anecdotal evidences, and experiential learnings of girls and women with disabilities; disability rights advocates, professionals, and institutions working in the SRHR sectors have suggested that girls and women with disabilities experience discrimination in realizing their SRHR (CREA, 2012). They are often invisible and marginalized within the sexual rights discourse in Nepal (Kayastha, 2016) for several reasons from social to practical.

Stigma and stereotypical perceptions regarding disability and sexuality remain a crucial role in limiting the sexual and reproductive health and rights of girls and women with disabilities. The general perception of girls and women with disabilities as 'Asexual beings' results in their SRHR needs not being recognized, in spite of the fact that girls and women with disabilities have broader and specialized needs due to added vulnerability. Girls and women with disabilities are reported to face a high degree of sexual violence (Puri et al., 2015) and are disproportionately vulnerable to intimate partner violence (Gupta et al., 2018). Studies have shown that young persons with disabilities have the same concerns and needs with regard to sexuality, relationships, and identity as their peers, and have similar patterns of sexual behavior and needs (Brunnberg et al., 2009). However, the conversation around sex and sexuality is strongly discouraged and aspects of sex and sexuality do not make it to the list of 'basic needs of women with 'disabled' bodies in the hierarchy of needs defined within the parameters of conduct set by abled bodies for abled bodies themselves. The bodies of women with disabilities are denied respect, agency, and personhood and are deprived of autonomy and the right to self-determination concerning their own bodies (Body and Data, 2020). Thus, women with disabilities continue to face a significant challenge in every sphere of their reproductive lives including pregnancy, childbirth, and motherhood due to the negative attitudes that undervalue women with disabilities and question their ability to control pregnancy, childbirth, and motherhood thereby limiting their reproductive rights (Devkota et al., 2019). Women with disabilities are discouraged or denied the opportunity to have relationships and bear/ raise children as they are perceived to be a burden; dependent on others as recipients of care rather than caregivers, and hence incapable of taking care of children on raising a family (WwDA, 2009). Furthermore, when sex is viewed from a biological viewpoint, with sex solely for the purpose of reproduction, and primarily reproduction of the 'fittest', it means that persons with disabilities are excluded (Higgins et al., 2012). Girls and women with disabilities in Nepal have reported being discouraged from bearing children guided by the belief that disability is caused by genetic conditions and hence girls and women with disabilities will bear children with disabilities (Simkhada et al., 2012). Girls and women with disabilities themselves have also reported anxieties and fears that the impairments (irrespective of types) would be transmitted to their babies (Devkota et al., 2019). A study further reported that such promotion and overall convention of marriage in Nepal defines the 'eligibility' of girls and women with disabilities for marriage unions. However, the study also found that though girls and women with disabilities are believed to be ineligible for marriage, children with disabilities are still and equally vulnerable to child/early/forced marriage as other girls/children without disabilities. Disability added an additional layer of vulnerabilities, as children with disabilities are married under highly compromised and vulnerable situations leading to more severe impacts on their lives (Plan International Norway, 2016). Many girls have

been subjected to forced and involuntary sterilization and forced abortions (UNFPA, 2007) and other inadequate, inappropriate, or harmful practices such as those related to pregnancy prevention and menstruation management (forced contraception; removal of the uterus); medication to suppress sexual desires, and Eugenics (Open Society Foundations, 2011).

While the social norms and the public attitudes affect the life experiences, opportunities and help-seeking behaviors of girls and women with disabilities (Devkota et al., 2019), on the other hand, the existing infrastructure and service delivery systems also possess considerable challenges for them to access SRHR services. Nepal's Health and Development Strategy (2000) does ensure provisions for availability of 'information, education and counselling' on SRHR for adolescents including adolescents with disabilities, yet information on SRHR (and sexuality) are none or little (Kayastha, 2016) and either not accessible to adolescent girls or socio-culturally barred (Morrison et al., 2014). The lack of inclusive education further prevents access to SRHR education for girls and women with disabilities, as sex and sexuality education are not included in special education curriculum (limited only to mainstream education). Though 'Accessible Physical Structure and Communication Service Directive' for Persons with Disability (2013), is in place, physical barriers (ramp, check-up tables, birthing beds, toilets, etc.) still continue to be the main factors hindering access to sexual and reproductive health [WwD Network, 2018; SRI, 2018)]⁴. However, though physical access is problematic, it is not a priority issue as compared to other factors that limit access, particularly for unmarried adolescent girls, which include stigmatization, lack of privacy, and confidentiality. Health care providers are reported to be unprofessional, and judgmental, and impose moral sanctions on sexual behavior and the need of adolescents (Pandey et al., 2019), which is also the case among girls and women with disabilities. Girls and women with disabilities have reported feeling anxious while accessing services as they have been discriminated and mistreated (WwD Network, 2018; Kayastha, 2016). The health professionals are reported to be often insensitive and behave inappropriately with complete disregard to their right to privacy and confidentiality. Girls and women with disabilities also do not feel safe accessing services, as there are reported incidences of sexual harassment during medical examination. Women with disabilities have also reported that health professionals are unaware of the needs of women with disabilities (WwD Network, 2018) while the health workers themselves also feels unprepared like in case of meeting the maternal health needs of women with disabilities (Morrison et al., 2014). The lack of knowledge and understanding on the SRHR needs of girls and women with disabilities and what works for them, is also a major factor that constrains effective response. This is because evidence on SRHR for persons with disabilities in general is sparse while women with disabilities are largely ignored in reproductive health research (Morrison et al., 2014; Hameed et al., 2020). Limited empirical evidences drawn directly from the lived experiences of women with disabilities themselves exists, apart from the anecdotal evidences or those informed by others' narrative portraying them. As a result, there is critical gaps in understanding on important factor like the health consequences of violence on women with disabilities in Nepal (Puri et al., 2015); what works to protect the bodily integrity of women with disabilities (Presler-Marshall, 2017) and what works for them in terms of SRHR interventions (Hameed et al., 2020).

⁴ Shadow report submitted to the committee on UNCRPD by women with disability network, Nepal (a group of 13 organisations across Nepal); Report Submission to the Special Rapporteur on Rights of Persons with Disabilities on Right of Persons with Disabilities to the Highest Attainable Standard of Health by SRI (2018).

3. Statement of the problem, scope, purpose and objectives

A strong lobby for recognition of SRHR of girls and young women with disabilities within the larger discourse of SRHR is gradually emerging, globally, regionally and nationally as well including in Nepal. This has led to an increased focus on inclusive and disability friendly SRHR programming. Disability right activists indicate that the number of SRHR services has increased in the recent years and efforts have been made to improve the quality of services (technical) including awareness/training for the health care service providers to ensure adolescent and disability friendly services (social). Investment has also been to ensure information are available in accessible formats (braille; audio; sign language). Better information access and availability of service centers (at least in the urban areas) are expected to improve access to the SRH services for persons with disabilities. Though specific studies to ascertain the extent of service accessibility were not found, OPDs / disability right activists involved in SRHR programming define that the access is quite low and shared that, *“even in urban centers where services are available in close proximity and even among educated right holders who are supposedly better informed through better access to ICT materials, communication technologies (computers, phone) or through their personal networks, the access to SRH services is still low. We wonder why?”* (Personal conversation, 2021). Little is known about the nature of this phenomenon— what (and how) ‘still’ inhibits the girls/young women with disabilities to access the SRH where measures to address the identified barriers such as physical access have been addressed. As indicated above, some factors such as stigmatization, privacy and confidentiality has been identified, but how these come into play is not yet fully explored. Some localized researches have been undertaken to understand the dynamics related to accessibility of SRHR and disability, but it is said to be *“mostly sporadic, done within specific programme context, to address programme need and not always appropriate to other context”* and *“gives some surficial ideas but not deeper enough to understand the intricacies”* [Personal conversations, 2021]. There is a need to unpack this reality further by exploring the experiences of girls and women with disabilities, to had better understanding on how the barriers exist in reality. Therefore, this study is undertaken with the purpose to explore the ‘lived’ experiences of adolescent girls and women with visual impairments (blind; partially sighted; low vision) with the following objectives:

The objective of the study: *Explore the barriers faced by adolescent girl and young women with visual impairments (blind, partially sighted, low vision) in accessing SRH services, with specific objectives to:*

Specific objective 1: To explore the adolescent girls and young women with visual impairments’ understanding and orientation towards SRH needs and services

Specific objective 2: To explore the adolescent girls and young women with visual impairments’ experiences of accessing SRH services

4. Research Methodology

Study approach: This study has adopted the qualitative exploratory research methods, which allow an in-depth inquiry into the ‘lived’ experiences of the research participants (referred to as ‘participants’).

Date generation and Analysis: For primary data collection, in-depth, ‘unstructured’ interviews were conducted in informal and casual settings, which allowed free-flow narrations as well as gathering of rich and thick data in natural settings. The raw data were analyzed as guided by the conceptual framework to identify key themes. The key themes and sub-themes are generated from careful reading and rereading of the interview transcripts. Themes and sub-themes are analyzed and interpreted linking them with the key objectives of the study and organizing them accordingly.

Sampling size and sampling technique: Following the purposive sampling principle, 12 research participants (Refer Annex 1 for the participants' profile)⁵ were selected for the study from the list of potential participants provided by Prayatna Nepal, ensuring a balanced mix by meeting the following set criteria:

- Age: Adolescent girls and youths between age of 18-30 years
- Marital Status: married/unmarried
- Occupation: students/home maker/working professionals
- Living with family; in hostel (groups), or living independently (alone or shared spaces)
- Geographic location (home district⁶)
- Ethnicity

Conceptual and methodological framework

This study follows the ICDP’s operational definition of SRHR and understands that it incorporates a wider spectrum of themes (areas) beyond just health care services to explain the overall well-being of a person. Based on this wider framework, the study focuses specifically on sexual and reproductive health services (health care) in relation to the dimensions of access to such services.

International Conference on Population and Development (ICPD) defines sexual and reproductive health as:

A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes
(UNFPA, 2013)

The conceptual framework of this study draws upon WHO’s AAAQ framework (WHO, 2016; Unicef, 2019) that defines **ACCESS** to health care services from a human rights perspective⁷. It states that in order to fully realize peoples’ rights, health services must be:

- Availability(A): available continuously and in sufficient quantity
- Accessibility(A): physically accessible and affordable to all without discrimination

⁵ 8 participants aged between 20-25 years; 4 aged between 26-30 years; 5 participants from ethnic communities ; representing 10 districts (home district)

⁶ All the research participants are currently residing in Kathmandu, but all are/were not permanent resident of Kathmandu. They are from district of Nepal, and are presently in Kathmandu for studies, job or relocated after marriage.

⁷ The human rights based approach to health is derived from article 12 of the international convention on Economic, Social and Cultural Rights

- Acceptability (A): ethically and culturally appropriate for all from different backgrounds and especially sensitive to vulnerable groups and
- Quality (Q): comply with applicable quality standards (Quality).

Among these four dimensions (domains) established to define accesses to services; this study specifically focuses on the third dimension only, i.e., on ACCEPTABILITY. Where (if) any aspects of other dimensions such as availability, accessibility or quality were found to interface with the dimension of ACCEPTABILITY, then those aspects are explored accordingly but within the domain of ACCEPTABILITY [and in relation to it, for *e.g.*, *access to information without discrimination (accessibility) relates to the domain of acceptability*].

We acknowledge that the various barriers to SRHR for persons with disabilities, which include physical accessibility and economic accessibility (affordability), continue to exist. Therefore, this study explores the following **RESEARCH QUESTIONS**:

1. *Even ‘When’ or ‘IF’ the barriers relating to Availability, Accessibility and Quality are addressed then what can still hinder ‘accesses’ to services?*
2. *What are the nature of these barriers?*

To answer above raised questions, the research participants residing in Kathmandu (the country’s capital) have been selected so that one considers that quality, physical availability and affordability as such may not be ‘the key barrier’ given the context of a metropolitan city. Thus, the study aims to explore and describe what other barriers “in addition” [to availability, accessibility and quality] are likely to exist pertinent to the “acceptability domain”.

Extensive literature review has suggested that a universal definition of “acceptability” that appropriately reflects the complexity and depth of the construct is yet to be emerged (Bucyibaruta, et al., 2019). The study is guided by the definition mostly used in context of access to health services which defines acceptability as *a multi-faceted construct that reflects the extent to which people receiving the healthcare intervention [and providers] consider it to be appropriate, based on their anticipated or experienced cognitive and emotional responses to the services* (Sekhon et al., 2017). Guided by this broader framework, the study approaches “acceptability” aspect of the services from the demand side of the system i.e., the perspective of the research participants as the recipient of the services [referred to as ‘user’ in the literatures]; and not from the perspective of the service providers (supply side which includes health professionals and institutions) or other parties (community perspective). Therefore, in simpler terms we are exploring **the participants ‘willingness’** to use the SRH services. This is done by exploring the construct of “accessible SRH services” as understood (expected) and experienced by the research participants themselves with the aim to understand how constraints (problems/challenges) unfolds while realizing disability friendly services. The emerging factors that unfolds have been broadly explored in relation to three elements of acceptability as proposed by Gilson⁸ namely:

⁸ Gilson L. Acceptability, Trust and Equity. In Mooney GM, editor. Cambridge: Cambridge University Press; 2007 as cited in Bucyibaruta et al (2019)

- a) **Patient-provider interaction** [participant's experiences and perceptions/expectations related to those who provide the services]
- b) **Patient-health service organisation interaction** [participant's experiences/ perceptions/ expectations related to the institutions providing the services] and
- c) **Patient-community interaction** [participant's experiences/ perceptions/expectations related to the community i.e. family, friends, relatives, members of the community who might positively or negatively influence the patient's acceptability of SRH services such as understanding, support or sanctioning] Gilson (2018).

[Note Gibson's framework uses the terminology 'patient' to refer to the recipient of services. In this study, the research participants are the recipient of the SRH services, and hence the term 'user' have been used to refer to them henceforth, instead of 'patient'. The term 'Participants' i.e. 'Research Participants' and 'User(s)' are interchangeable used in this report]

We understand that 'Acceptability' of services includes both 'social acceptability' (conformity to social preferences as expressed in ethical principles, values, rules and regulations) as well as 'individual acceptability' (individual preferences) and while one can influence the other, the two does not always match (Donabedian, 2003), in which case the participants' perspectives take precedence.

The literatures have suggested that indicators of acceptability of services include physical factors which are the dependent variables (The Danish Institute for Human Rights, 2017), whereas other variables like the demographic and socio-economic status of the population; such as age, gender, marital status, education level and poverty are independent variables such that these factors are not directly related to the definition of acceptability, but are likely to have significant impact on it, either positively or negatively (Bucyibaruta et al., 2019). It clearly indicates that such independent variables also include disabilities. Therefore, the study aims to explore factors related to acceptability in relation to "disabilities" i.e., if and how it adds *additional layers*. This is in accordance with the Human Rights Based Approach (HRBA) where the human rights principle of non -discrimination applies equally to all AAAQ criteria as a crosscutting theme. *Therefore, here we seek to explore and describe the nature of discrimination in accessing SRH services, based on the types of disability.*

Limitation (and scope) of the study:

- Owing to Covid 19 safety protocol, all interviews were conducted online via Zoom, without any visuals. We believe, this was helpful in some ways to increase privacy that helped the participants to open up in their conversations. However, we felt that that inability to pay attention on non-verbal data and observations due to virtual interaction caused some limitations for making better sense of collected data.
- This study covered only the SRH 'services' aspect of the overarching sexual and reproductive health and rights of persons with disability, which was precisely focused on the "access" aspect of it. Within the various dimensions of access, as presented in the framework above, the study explored only the 'acceptability' dimension.

- The ‘acceptability’ of the SRH services among girls and women with visual impairments is explored from the perspective of the service recipients themselves (research participants) [demand side] and not from the perspective of the service providers [supply side].
- Despite the attempts have been made to ensure diversity among the research participants, it needs to be noted that the research participants have been recruited from a very small pool of potential participants provided by Prayatna Nepal from their own network. Further, we acknowledge that it is important to explore access to SRH services from an intersectional perspective as well [ethnicity/caste/class and other social identities including sexual and gender identities (SOGI)], but an intersectional aspect could not be explored within the present scope of the research. The participants were not asked to specify their social identities including sexual and gender identities nor any inquiries were made around it. This study thus, does not intend to explain the dynamics or the complex realities of a disabled person’s sexuality nor does it explore the intersectional discriminations and marginalization in access to SRH services.
- This being qualitative research, the study attempts to present the research participant’s individual perspective on the phenomenon under study rather than to generalize the findings. Further, since the findings are based on the experiences of only girls and women with virtual impairments, the findings are more relevant to girls and women with visual impairments and may not be generalized in case of other types of disabilities. However, some inferences maybe drawn in terms of how gender, disability and SRH services interfaces.
- This study is exploratory research; it also does not detail the complexities or explain the dynamics within each of the key themes identified in this study. It rather focuses on exploring the key themes, which may give some direction in specifying areas for future research.

Research Ethics: Research ethics has been strictly followed with necessary safeguarding measures in accordance with the Ethical Standards in Research⁹ at different stages of the research. This includes approaching and engaging the participants; data collections and data storage (informed and voluntary participation; safety- ‘do no harm’); and presentation and dissemination (maintaining confidentiality, anonymizing data, and secured storage, etc.). A consent form outlining the details of the study, the ethical protocol, and rights, and the safety of the participants were read out to the participants and signed by the researcher securing the written informed consent voluntarily.

⁹ <https://www.city.ac.uk/research/support/integrity-and-ethics/ethics/principles>

5. Key findings

The findings from the study suggested that girls and women with disabilities have been struggling to access even essential health care services such as services and facilities required for addressing their sexual and reproductive health care. The results of the research were analyzed and interpreted by adopting WHO's AAAQ framework and ICDP's operational definition of SRHR. The results are categorized into several key themes and sub-themes as they emerged from the collected data. These include understanding and orientation towards SRHR to challenges and difficulties that participants face while accessing SRH service and facilities in their respective communities.

5.1 Understanding and orientation towards SRHR

This section explains the participants' orientation towards SRHR, inquiring into various aspects that is likely to affect their understanding and perspective, such as social narratives and early education, as well as participants' own narratives and perspectives in relation to SRHR. For instance, when they learned about basic ideas of the SRHR, how it felt to them, when they first learned about SRHR.

5.1.1 Early education and information: Source and relevance

Evidence from the research has highlighted that participants shared that they got to familiarize themselves with the broader concept of sexual and reproductive health and rights, formally, much later in life—mostly through the SRHR trainings. Recalling from memory, a participant shared *“I started to know about all those things since last two years only. Before that, I was aware about mensuration only, not more than that”*. The school level curriculum that includes SRHR¹⁰ and participants mostly recall learning about reproductive organs, menstruation cycle and contraceptives (types of family planning device). However, the school education is reported to be ‘just for the sake of it’. Thus, school level learning on SRH was not effective to impart essential knowledge on SRHR. It is not taught, per se, based on experience another participant explained as *“we were asked to read the chapter ourselves, unlike other subjects where the teachers did not feel comfortable to explain in class “and adds “both teachers and students were shy”*. This scenario clearly explains that SRHR issues are not considered as a public issue in the classrooms as well. It is rather perceived as a private, personal and to the extent stigmatized even today.

In addition to school curriculum, one of the participants shared listening to radio contents while another one said about attending SRHR sessions organized by one of national organization working in SRHR (students were taken for weekly sessions). Similarly, another participant also mentioned a nurse who visited the girl hostel to talk about SRHR. Whatever little information is available through the formal channel (schools) happens to ‘be - too little, too late’, as the participants said, *“we get to learn about menstruation only in class 8 or 9 whereas most of us have our period already in class 6”*. Similarly, the SRHR training offered by the NGOs is also reported to be late especially for the adolescent girls as the participant shared, *“most of the trainees are past their adolescent age. Younger girls need to learn more about the natural changes in their bodies while our need is more related to the problems we face”* and adds further *“at this age, we are concerned more about the problems we are facing, while in the SRHR training, we talk more about*

¹⁰ Class 7 and 8 content is said to include just general introduction to health and hygiene (course on Health) while class 9 and 10 include content on reproductive health (course on Health, population and Environment).

the bodily changes, menstruation hygiene, contraceptives and, of course, sex and sexuality on a conceptual basis. It would be good if we could talk about the problems we are facing".

Elders- sisters, sisters-in-law, and aunts (usually not mothers¹¹) are identified as the first ‘educators’ and ‘go-to-person’ but the conversation on the issues of SRHR as such is not usual. Participants do not actively solicit information, guidance or advice from family members unless there is some health concern, that too hesitantly. Only those girls who are not living with families [in hostel; rented shared spaces] share talking about SRHR but that too discreetly. For information concerning sex and pleasure, friends are said to be the main source of information. Only one participant shared searching for information on the internet while few others shared getting the information from materials (magazines, romantic novels, films, radio etc.).

5.1.1 Curtailed and mis(guided) narratives

Findings from the research suggested that the narrative which prevail in communities and societies regarding disability and sexuality in general and about SRHR of girls and women with disabilities are curtailed and misguided to the large extent. The information the participants received from the immediate family members are very limited. Mostly it is limited to menstruation, that too not so much related to health, hygiene and reproduction but more in relation to social conduct (such as practicing social isolation). Even the married participants, who lived with their parents until getting married, shared they did not receive any information on sexual and reproductive health from the family members before getting married. Thus, the cultural aspect also remains crucial for sharing or discussing issues of sexual and reproductive health.

Participants shared that, though all of them had heard about menstruation, they did not know what it actually was until they had their first period. This practice did not help them to develop even essential understanding about their own physiological and psychological changes that occur at the adolescent stage and did not well prepare them to handle their personal health and hygiene. This issue is rarely discussed openly and publicly as it is perceived as personal and stigmatized subject. Not only that, the mental health and psychosocial effect of such practices on girls and women with disabilities is seldom discussed in scholarship and development discourses too. All the research participants commonly mentioned that they learned that one is supposed to remain in isolation from others during menstruation, which they had seen other female members in the family also do. The participants shared:

“I had my first period when I was playing. As I did not even have essential understanding about it, I thought I must have hurt myself. I did not know girls menstruate.”

“I knew girls go through period but I did not know what it was. When I had my first period, my mother handed me a piece of cloth. I did not know what to do with it, so I inserted it in my vagina.”

“When I had my first period, I thought I was having diarrhea from my vagina.”

¹¹ Only 2 participants identified mothers as the go to person (both living in hostel since child hood)

“My sighted friends watched while I menstruated. Everyone gathered around me and I used to say...wait... wait here it comes. Here it comes and they would go. Yes...yes. It's coming, it's coming.”

“My mom, while telling me about menstruation, told me that when the time comes then I will get a tika¹² in my forehead. I kept wondering, how I will get that tika. “

They also shared how they grew up with misconception regarding the topic,

“I studied in co-ed school so when any male members came nearer to me, I used to become scared. Even I used to keep distance from my father.”

“When I reached grade 9 then, we [friends] started to talk about sex. We were told that we will be pregnant even if we use the same toilet used by males.”

None of the participants, except one, were aware of the recently revised abortion act¹³, while two shared having heard about it but not familiar with the provisions. They also held misconception regarding the provisions as they shared,

“Is it true that you need the husband's permission to get abortion?”

“I heard that it is difficult to get abortion if you are not married.”

Participants are however aware of risk of unsafe abortion as one shared,

“One of my friends, who is also visually impaired, was pregnant and she was unmarried. She was looking for the place for abortion. She was not aware of where to go, what medicine she needs to use to abort the baby. She didn't share with any one and brought medicine from medical shop which created complications due to excessive bleeding”

5.1.2 Feeling of fear, shame and discomfort

Evidence has suggested that participants felt fear, shame and discomfort when it comes to discuss and share regarding SRHR issues in their communities. This issue is rarely discussed among family members openly and comfortably more so with members of opposite sex—father, uncle, brother—due to narrow or partial understanding of SRHR. Some of the participants who have participated in SRHR trainings/orientation shared that the trainings have enabled them to open up, yet all expressed extreme discomfort in openly discussing on the topic of SRHR (this included training participants). One participant, while sharing her experience of SRHR training shared, *“I felt why are we talking about the same thing over and over again when we already know about it”* and when inquired further why such feeling? Was it because you already know enough or was it because of the discomfort, the answer was *“the discussion makes us uncomfortable”* particularly when it comes to interaction among family members and with male members in the communities. This is equally true in case of girls and women without disabilities as well.

Discouraged narratives: Participants hesitate to talk about searching for information online or inquiring about it with elders, which also includes friends and seniors [in the hostel] as the response

¹² Red dot put on the forehead usually as a blessing from God. Whereas it also symbolizes married status among women (especially red tika).

¹³ Safe motherhood and reproductive health right act (2018)

they receive includes “*you should not be talking about such things*” or “*you are still young to ask about these things*”. Participants think that anyone taking such interest will be considered characterless as they have heard their seniors and friends’ comments “*oh, so now she is starting to go out with boys*” or “*she has had sex*” when someone tried to inquire about it. *Participants feel that such conversation is not encouraged, done only discreetly as it is considered bad as they shared their experiences.*

“When I brought out the topic, my friends say chyya [nepali expression for feeling disgusted or ashamed or shocked] what are you talking about, but I know in private all of them watch such content in internet.”

“We do talk about sex, but only among very close friends. I feel that such discussion will be taken negatively...”

Concerns for confidentiality: Participants indicate that they refrain from discussing about SRHR because they fear that it will not be kept confidential and they will have to face judgment about their character, as one of the participants shared,

“I fear they will spread the word” and adds, “we hear people commenting how characterless they are. So most probably they will say the same thing about us with others” while another adds “I don’t share as they will make an issue out of it.”

Fear concerning adulthood and violence: Parents, family members and neighbors have however talked to the participants about possible risk of sexual abuse from the very early age with statements like, “*Don’t go out. People will touch your breast*” and “*How are you going to protect yourself if you are alone?*”. All the participants have also heard stories of violence against girls and women with disabilities. Most of them have also experienced some form of violence themselves from a very early age, though they were able to identify it as violence only later in life. In addition to the experience of violence, participants have also heard many stories of violence as participants shared:

“When I was in grade 7 or 8 there was one person who used to come close to us and one day he came to my bed and wanted to sleep there. That time, I did not know about the intention of that person. I just thought that he was so caring about us. Only now, I realized that his intention was bad.”

One man always used to travel with me and sat close to me. Now I think that was abuse but that time I felt nice when he touched me”

“One of my friend, who is visually impaired, shared that one day when she was coming back from college it was late and dark, she asked one pedestrian to help her to cross the road. During crossing, he touched her breast, but she could not resist him as it was raining and she needed help to cross the road. How people take advantage of it. Hearing of those incidents I feel so scared I might be abused.”

“My friend’s parents were abroad and both sisters were staying with their paternal uncle. She was just 10 and her sister was only 8. They both got raped by their uncle. When she was at the age of 18 or 19, only then she got to know that activities done by her uncle was rape.”

Based on their experiences, participants explained menstruation particularly first one as more negative. Majority of participants stated as it to be a very traumatized experience specifically because of the initial response of others towards it and the anticipated fear. Furthermore, they

associated it with the feeling of distress because of the anticipated fear of being ostracized. They recall being teased with comments like “Oh you have grown up now” and also warned “*Now we will not eat the things touched by her*” and “*Stay away from male members, they should not see you when you are menstruating*” and the continued stigmatization they face. Majority of the participants recalled crying when they had their first menstruation because they thought one was supposed to cry and also out of fear of what was going to happen next (anticipated fear of restricted movement; isolation, social ostracisation) as they shared:

“I cried... no, not because of pain. But I have noticed my sisters do the same, so I thought that’s what one is supposed to do when they are in their periods”

“I cried because I was scared, I did not know what was happening to me. Also, I heard that you are not supposed to touch anything, or/and meet any male members.”

Participants further recalled the looming panic, fear or sadness when the news was first broken mainly owing to concerns regarding the “ability” of girls with disabilities to cope with the eminent hardship and violence as the participants shared:

“When I told my mother about my menstruation, she was so worried and cried a lot about how I would manage it. Even our neighbor came and said same thing which added more stress to my mom.”

“During menstruation we are very much stigmatized that there might be bloodstain on my clothes or place I sit on. Because of those things, we are afraid to go out during menstruation time. It’s more stressful for blinds and visually impaired as they can’t see.”

“We can’t see so it’s not easy for us to manage it.”

5.1.3 Contradictory narratives: Orientation towards SRHR

The research results suggested that participants acknowledged that sexual desires are natural and essential for all and it is not different for persons without disabilities. They shared their curiosity and interest in exploring it as participants shared:

“Even before marriage, I knew about the sex and sexuality as my friends used to share about that. They used to share that during intercourse, it is very painful but later on, it is enjoyable. My friends shared their sexual experience with their boyfriends and I used to enjoy listening to their conversation.”

“I always used to think how it feels, what kind of experience it would be? Among friends, we used to share that we should have to experience it once. With friends (girls), we used to play among ourselves roles of boys and girls.”

In addition to recognizing the SRHR needs, they also emphasize on the need to be open about it and challenge the myths as they shared:

“There is no difference between visually impaired and other people regarding sexual needs. That is natural so it is not that we do not have that need. However, there are so many myths that if you marry with visually impaired then your child will also be visually impaired”

Though they emphasized on the need to be open to express it, the participants also share the feeling of being shy talking about it (as discussed in section above), as a participant share:

“My friends used to share sexual relationship of their parents though I can’t see but I used to enjoy a lot hearing about it. When I started to understand about sex and sexuality from that time, I felt shy to talk about those things”

Furthermore, participants are aware of their SRHR needs, are confident and defines SRHR as “physiological, psychological and social well-being” and something “related to the entire life of a person”. Yet the same person says “SRHR is a separate thing [indication other than the usual things]” “it’s different, not like other topics”

Another participant did emphasize the importance on conversation, especially among friends as a means for satisfying their need but then she did wonder,

“Conversation helps us untangle the sexual desire suppressed deep inside, yet my friends think I am characterless when I try to talk about these things. Why can’t we, at least, talk about it and satisfy our curiosity”

The study participants emphasized on equal rights of girls and women with disabilities and have also shared experience of challenging the society’s perceptions¹⁴. However, at the same time, they also shared experience of upholding the same prejudiced values and norms. They shared their fear that they are less likely to get married as they shared “for blind people, it’s always fear that we might not get married” and “I fear, who will take care of us”. Their narratives also indicate the need to uphold and challenge to some extent that the prescribed social norms about sex and marriage.

“As you come of age, it’s natural to feel curious about these things. Even just a praise from a boy, ‘oh. You are so pretty’, makes you excited. Even when someone comes and sits beside you, when you feel they touch your back, you feel so good.... I have made online boyfriends and during chats, they ask me to touch myself, which makes me feel good. I have been satisfying myself like this. We do not have access to tools for self-pleasure like sex toys. Online friends ask me to meet in person. Sometimes I feel like going, but I have controlled myself. But next year I am going to really experience it fully...as next year I am planning to get married”.

“I have met some people who talk about sex and ask about my opinion like is this important or not. I was bit surprised that few of my Facebook friends asked for sexual relation, and then I have blocked them. I felt that is violence.”

“I have been in relationship but we never had intercourse but sometimes we talk about sex and do sexual act. There is curiosity and obviously, I do have desire of sex so somehow, we have fulfilled it.”

“I had one partner with whom I talked about sex but never had sex with him.” But later on, we broke our relationship.”

On the other hand, participants did emphasis on “trustworthy” partners with ‘mutual respect’ and ‘confidentiality’ as key aspect in perusing any relationship before marriage (which can be an

¹⁴ As in case where comment were made with regards to motherhood (Refer to the section on user-provider interaction)

indication of ‘hesitation’ or ‘caution’ owing to the fear for disclosure of such ‘socially unacceptable’ behavior, as the participant shared:

"Generally, for visually impaired women, it's difficult to get SRH services. When we reach to certain age, we do have sexual desires. So, to fulfil that desire, we either have to get married or have to look for the partner who is trustworthy. If we get a partner, then have to be aware it is safe or not. Before marriage, it is always issues of confidentialities. There are so many persons with visual impairments whose marriage is delayed due to his or her disabilities. Sexual desire comes when they reach a certain age so they look for a partner for sexual relationships. To fulfil their pleasure, some people are able to get but most of the visually impaired people are not aware on safe sex and contraceptive."

Further, owing to the hardship and their own experience of violence and those of others, which they also fear upon themselves, some narrative also emerged that justified consequential violence against women with disabilities, inflicted in the name of protection as two of the participants narrated,

"I have heard that parents remove uterus of their blind daughters. There was one blind student in my hostel. The warden found out she was pregnant when her stomach started to grow. Her own uncle had got her pregnant. Later we learned that her own people got rid of her [murdered?]. When I hear stories like this in a way, I feel it's a good thing to get the uterus removed. I feel, who knows, I myself also can be victim of such violence."

"One of my friends usually says that she is very much fed up with menstruation so she feels like removing her uterus."

5.2 Experience of accessing SRH services

This section explores the participants' experiences of realizing SRHR service, particularly in relation to their engagement with the health care providers, inquiring into aspects such as their orientation towards SRHR products and conduct of the service providers. Participants' own experiences as the primary service recipients, as well as experiences of others, to which they have been a witness to or the heard narratives (stories, anecdotal accounts) which are likely to affect their perspective as (future) potential user or services are explored.

5.2.1 Service availability and accessibility

The availability and accessibility of needed services remained one of the key challenges for girls and women with disabilities when it came to SRHR concerns. Participants confirmed that barriers do exist for accessing SRH services for girls and women with disabilities, but they were less related to physical availability. Physical availability as such was not a main issue as they were aware of the availability of the services- what is available and where or how to access them. However, accessibility of the required services was reported as a key concern. Similarly, one of the participants shared lack of availability of product for self-pleasure such as sex toys is also equally challenging. Some concerns, however, indicated about the accessibility of the services, owing to disability (visual impairments) such as the need to:

- rely on others to access the services (cannot independently reach service centers) as a participant shared “yes, there are many clinics, but how do we reach there on our own”
- lack of products adaptation such as in case lack of information on expiry date as participants shared,
“None of the information are available in braille, so we do not know if or when the products expire”.

5.2.2 Service acceptability: Orientation towards use of SRH product/services:

In addition to the issue of physical availability and accessibility, which is not indicated as the prime concern, what emerges strongly in all the narratives is related to factors that have affected or are likely to affect the service acceptability i.e., willingness to use the services.

Misinformed and misguided fear: Participants shared their fears of using the products like menstrual cups, largely owing to things they have heard (and hence anticipated risk/fear) as in the case of menstruation cup (moon cup). All the participants who have attended SRHR trainings have been oriented on the use of the product but none of them has used it as some of the participants said, *“I heard it's painful to insert it so I did not try it”* or *“I heard it gets stuck inside”*. During the trainings the participants have been taught to use the menstrual cup (practiced it folding it their hands), but no practical demonstration (using dummies or other means) have been done. All the participants are aware of contraceptives including emergency contraceptive pills (I-Pills), but appear to have less trust or interest to use it. Even the married women shared much confidence in the ‘natural withdrawal methods’ during sexual intercourse than the use of available contraceptives. One of the participants shared discontinuing after some years of use and reverting to the natural withdrawal methods. Younger participants shared their concerns stating,

“I have heard that if you use contraceptives now, you will have problem later getting pregnant”.

Service deprivation: None of the participants have reported going for general medical check-ups and have only visited health clinics in case of problems, and not unless it is critical. They shared hesitation in sharing their problems with the parents and seeking medical help. They avoid visiting doctors to the extent possible as they have been counseled by family to “resolve the issue at home” as participants have shared:

“During menstruation I have severe pain. However, as advised by my mother I take enough rest and use hot water bag for comfort. I never consulted gynecologist. I think my mother advises that way fearing what other people will think”

“I am shy and afraid to share with people as this is bad thing happening with me”

“When I had white discharge, I told my mother and she advised me to clean frequently instead of seeing a doctor. Sometime we feel shy/ afraid to share our problems with parents”.

“When I had breast pain, I could not share those things with my family, but for two weeks I went through psychological stress. So, it's very important to make girls aware on their bodily change and its effect.”

“Sighted people can just go to the pharmacy and just point at the pills and buy, but we have to ask for it. We feel shy to ask for it. I have heard that mostly boys go to buy I-Pills.”

The need to have someone accompany the participants to assist in use of the service, owing to the visual impairment, which compromise one's confidentiality is thus a key concern as the participants share,

“Sometimes we might need contraceptives, and at that time it might not be possible to go alone and get those things. If we take someone with us it's also not easy to ask for contraceptive in front of others. Or there might be possibility of unwanted pregnancy so at that time for a checkup we can't go alone and if we take someone, we might lose our confidentiality so those stress is always there. It's not easy to go to hospital and get healthcare”.

“We heard that there is excessive bleeding during abortion, so you have to take along someone with you. The friend I accompanied for abortion was told by the clinic to bring someone along. So, she requested me to go with her. I feel it would be good to have similar services like in the case of covid-19 infection where everything was taken care by hospital officials. We have seen that ambulance comes, takes the patients and bring them back. So, it would be good if we also could just call for the service and there is someone from the hospital to take care of everything. We don't need to take anyone with us.”

5.2.3 Service acceptability: Experience with the health care providers

During conversation, two of the participants shared that their experience at the health service facilities were good and they did not have any bad experience, the rest shared that their experience was not so pleasant. They either have had unpleasant experience themselves or have heard about friends' experience. These include:

Demeaning behavior: Participants used the word “differently” to describe the conduct of the service providers towards them and explained they feel they have been treated differently than others. They have experienced delays in being attended and have been made to wait longer than others. They are aware of the fact that hospital (and any other services) are mandated to give priority to children, elderly, pregnant women and persons with disabilities, however, they said that, “this does not happen”.

The participants also described their feelings of being ‘teased’ by health professionals, and explains that to include being ridiculed with reference to sex and marriage (‘pre-marital sex’) and treated in a demeaning manner as the participants stated:

“At the door itself, the doctors ask why are you here? Did you come after sex? Are you married?”

Participants have heard similar stories of their friends as well,

“One of my friends had white discharge problem and I went with her to see the doctor. While examining her doctor inserted her fingers into her vaginal. When my friend screamed with pain, doctor scolded her saying ‘when having sex, you didn't have pain now while checking you feel pain’. She never had sex.”

The participants also shared of being discouraged and ridiculed for seeking services, hinting that they do not ‘need it’ as participants shared,

“One of my friends went to get her vagina checked, as she was having some problem. She felt it was smaller than normal. But the doctor scolded her saying ‘it's okay, what better do you want than this’. We are blind and have never seen or know how the vagina look like. How are we supposed to know?”

“When we go to seek services like to get I-pill or to get pregnancy test we get comments like “why does persons with disabilities need this? Or Is it possible with persons with disabilities?”

The research also found that comment were/are passed on to girls and women with disabilities emphasizing the notion that such individuals are weak and incapable, therefore, they are unfit or unable to bear children. Consequently, this leads to providing suggestions for abortion and avoiding future pregnancy. According to participants, they did not receive proper (pre/post-natal) care or attention as the doctors believed that they were not capable of caring for their children. One of the participants further explained her experience,

“A nurse asked me, are you married? Do you have a baby? Then commented you cannot see why you gave birth to a child? Then I replied to her do we give birth to child from our eyes? You don’t know from where we give birth from?”

Others shared similar experiences,

“That doctor just commented that why people who can’t see can have a baby, why don’t you abort? If we don’t have any problem having baby, then why other people feel pity on us. Though most of the hospitals and healthcare centers say that they give very good services and there is no discrimination but most of health service provider have negative attitude towards persons with disabilities”

“Once I had white discharge and went to hospital a nurse behaved very rudely with me and said why you people want to give birth to a child, who you will think would be able take care of your baby. I told her why don’t you just do your duty?”

“My friend went for delivery. When she was screaming nurses very badly scold her why you want to give birth to a child if you can’t bear it.”

The perception extends beyond health workers as well. Another participant shared similar comments made by people who were not healthcare providers in hospitals,

“I did not have much trouble during pregnancy, but when I was 5 months pregnant and had to stay in hospital for five days due to stomach pain, I didn’t experience any bad treatment from doctors or other people. But other patience commented that how I will manage my baby”

Concerns for Confidentiality: Participants further indicated the issue of privacy and confidentiality, rather strongly, as being a key concern in SRH services. The results have identified privacy as a key issue, which relates to the physical space like secured space during check-up and counselling. This is also a concern for the participants who share *“while the doctor checked me, I felt uncomfortable as I could not see who else was in the room. I could hear them talking to each other”*. However, here the issue is related to the ‘conduct of the service providers towards girls and women with disabilities’ rather than the physical space. The narratives reflect that mainly the doctors themselves and other healthcare providers have not been able to assure the users of the needed privacy and confidentiality as participants shared:

“I wanted to share one very bad experience of my life. After 4-5 years of marriage, last year we planned for baby so my husband and myself decided for fertility check. We both (my husband is also visually impaired) went to XX [reputed maternity hospital] with one of my sisters for the test. My husband collected his semen at hospital and was about to take that to the lab when one of the nurses asked us to leave that sample at table and said she will take that to lab. So, we left it on table and

left. After one week when we went to hospital to collect the report, they said they have lost my husband's semen. We complained to the hospital doctor but nothing was done. I felt like crying. There was no privacy and also we lost our trust towards the hospital".

From the interactions that they have had with the healthcare providers the participants share that they feel they cannot trust the healthcare providers as they believe they will not maintain confidentiality as they shared:

"The doctor there said that so and so couple comes here often. So, when they can disclose their names to us, they can also disclose our names to others. Besides, the disability community is very small [closed] and everyone knows everyone. So, we are concerned about confidentiality"

"When we were in the clinic the person there asked us how we came to know about the clinic and insisted on disclosing the name of the person who informed us about this clinic"

In the training, the doctors who came to take the sessions, indicating to one of our friends said I 'have met you before' in front of all of us. This is a breach of confidentiality."

Experience of Violence/Abuse: Participants have also shared experience of being violated during check-up, which ranges from verbal comment on body and being touched inappropriately as the participants share:

"Just because we are blind they treat us this way. We know when they are touching us differently than what is needed for check-up"

"The doctor made comments like: "you are so beautiful but how come you are blind"; "Even though you are blind you have maintained your body so well" and touched my cheeks"

"My friend shared that the doctor groped her breast."

The results have highlighted that such experiences has discouraged participants and created a sense of fear as one participant shares,

"When we hear such comments, it disheartens us."

6. Discussion on "Acceptability" of SRHR services: Expectation with regards to 'disability friendly SRH services and its barriers

In this section, we analyze the interplay of the factors that affect service acceptability in order to further understand the nature of the barriers faced by girls and women with disabilities. Furthermore, we explain participants' understandings and expectations of "disability friendly SRHR services" as shaped by their lived experiences and explore factors that have impacted their attitudes towards SRHR services, and the way they define, identify, prioritize and meet those needs.

7. Shaping of adolescent girls and women with disabilities' expectation of SRH services

The emerging narratives of the participants specifically indicated towards two key actors and the interaction with them when they refer to SRHR and services. This included interaction with community [User-community interaction] and interaction with the health care providers [User-provider interaction] whereas interaction with the institutions [User-institution] as such was not indicated particularly as a defining factor. "Interaction" refers to the exchange (comments, exchange of information) the participants have had with these actors, including the response or reactions to certain events and the treatment or the behavioral conduct towards them.

7.1.1 User-community interactions: Orientation towards SRHR needs and solicitation of services

The deconstruction of the participants' narratives of their engagement with their community [user-community interactions] indicates towards the following emerging patterns in relations to the SRHR services:

Problematizing SRHR; Stigma and fear: Participants used the words like shame, discomfort and fear to describe their experiences of SRHR. Beginning from the early memories of menstruation to the continued narratives and practices built around embarrassment, secrecy and fear, girls and women with disabilities are bound to approach adulthood, sex, sexuality and reproduction as “different”, not normal and something to be avoided.

The social narrative that “Sex is shameful” and “sinful before marriage” that dominates the participants' experiences nurtures this feeling of shame. Participants are made to feel embarrassed about being an adult, with comments like “now you are grown-up” when girls have their first period, associated menstruation with adulthood, with indirect connotation to sexual maturity. While, on the other hand, any interest and inquiry around it are strongly discouraged. Even the formal education on SRHR is cloaked in secrecy and embarrassment. The training/orientation in SRHR comes on only later in life [not following the life cycle approach, that call for age-appropriate information emphasizes that SRHR needs changes along with age]. Even in cases without any physical discomfort or pain, the experience of menstruation is described as traumatic. Parents and even neighbors react to the news of menstruation as an onset of a ‘difficult phase’

With the onset of adulthood, the narrative also starts including ‘violence’. This, together with participants' own experiences of abuse, is likely to further instill fear. This narrative of violence is more intensified when it concerns girls and women with disabilities because of the parallel narrative that, “all girls and women are vulnerable but girls and women with disabilities are more prone to sexual violence and they are not able to protect themselves”.

The stigma and the culture of silence attached to SRHR; attached apprehension and trepidation of possible violence problematizes the SRH services itself, affecting the process of identification and prioritization of SRHR needs. Participants emphasize SRHR as an important aspect of one's life, yet the same value is not reflected when they share their experiences of accessing the SRH services. The interplay of the social narratives that stigmatizes SRHR, participants own experiences is cloaked in embarrassment and fear of being judged [as characterless] and their own felt need to uphold social values and norms (around sex and marriage) as well as the PROTECTIONIST approach towards girls and women with disabilities leads to SRHR problems not being considered as ‘normal’ in comparison to other health needs. Normal and natural physiological functions like menstruation is considered as, “something bad is happening to me”. Such problematized notion of SRHR means that SRH services are solicited only when it's a ‘problem’, only in situation which can no longer be avoided and or dealt by oneself, within the privacy of one's home.

Girls and Women's autonomy/ compromised agency: The family members act as the ‘gate keepers’, playing a key role in deciding/prioritizing the need. Girls and women with disabilities are not only shielded from information but also from accessing the services. Girls and women with disabilities themselves have little say on it; even though they ‘know’ about the services and think, they are ‘important’ for them.

Even in situations where the participants were able to decide for themselves, the need for someone to accompany for the services still hinders their autonomy in decision-making as it compromises their confidentiality. This deprives them the right to self-determination and autonomy soliciting and realizing health care services.

7.1.2 User - provider interactions: Experiences of realizing SRHR services and its barriers

The participants experienced of engaging with the service providers [user-provider interactions] indicates the following concerns (indicating) barriers in accessing the SRHR services and the resulting perceptions and expectations from the service provider in relation to service acceptability

Risk of violence (Concerns for safety): Girls and women's experiences of being sexually violated by the service providers is one of their concerns. They feel that the service providers have taken the liberty to take advantage of the 'situation' where they are perceived to be at a disempowered and vulnerable position due to disability. This adds another layer of apprehension and hence wellness in seeking SRH services.

Breach for trust (Concerns for privacy and confidentiality): Girls and women's experience with the health care providers indicate that their expectations for privacy and confidentiality are not met. The healthcare providers' conducts do not provide them the needed assurances that their privacy will be respected. These experiences have reinforced their fear and apprehension and further strengthened their conviction that the service providers cannot be trusted. Not only their own experiences but also that of others fuels their apprehension towards the services and discourages them as evident from the expression "*such things...disheartens us*".

Lack of dignified service; Humiliation and discrimination (Concerns for dignity): Participants recalls being ridiculed and discouraged for SRH services by the healthcare providers, which also includes senior doctors. Firstly, the participants' experiences indicate that the service providers also uphold the same community prescribed notion that "sex is shameful and even more so before marriage" and the belief that "everyone coming for the SRH services have had sex" [hence the question "did you come after sex?" immediately followed by "Are you married?"]. Additionally, participants' experience with the healthcare providers also indicate towards the deeply rooted prejudices amongst the healthcare providers against girls and women with disabilities; largely reflecting the preconceived notion influenced by the social narratives around SRH (as discussed above). The underlining notions, which appears to guide their conduct towards girls and women with disabilities include:

1. 'women/girls with disabilities are asexual' and hence do not need SRH services [hence questing solicitation of services like in case of emergency contraceptive pills and pregnancy test]
2. Premarital sex is shameful and since girls and women with disabilities do not get married all girls and women with disabilities seeking SRH services are likely to have committed sinful act [hence checking marital status]
3. Girls with disabilities cannot manage motherhood/child care and hence should not need reproductive health services [hence advice to avoid motherhood]

So, the conduct of the healthcare providers towards girls and women with disabilities is largely guided by the orientation that '**girls and women with disabilities cannot and should not**' be

engaged in sex and reproduction and hence does not/should not require SRH services. This has implication on who is considered “ELIGIBLE” and hence “ENTITLED” for the services. This deeply rooted socio-cultural norms and beliefs around sexual and reproductive behavior (generally regulated through the institution of marriage) is one of the causes. Additionally, the value judgment with regards to the girls and women with visual impairments and the subsequent moral policing leads to girls and women with disabilities being subjected to an experience that dehumanize women with a ‘disabled’ body and effectively disfranchises girls and women with disabilities from the SRH services.

7.2 Acceptability of SRHR services: Expectation of “Disability friendly SRHR services”

The findings and the discussion presented above indicates that while physical access still remains a challenge for some girls and women with disabilities, what emerges as a prime concern is not physical accessibility or economic affordability but issues that relates to acceptability of the services. The acceptability of services i.e. whether or not, girls and women with disabilities are willing to access the services, are largely defined by their life experiences which are shaped by the social relationships and the interactions they have with the community at large [user-community interaction] and the service providers [user-provider interaction] which accessing the services.

The girls and women’s interaction with the community defines their understanding and orientation towards SRHR and how they approach the services whereas their interaction with the service providers shapes their expectation and acceptability of the services. Problematization of SRHR; fear of being stigmatized coupled with lack of agency for making informed choices means that SRH services are not openly solicited. Hence, privacy and confidentiality are of utmost importance in seeking SRH services. However, the participants’ experience with the healthcare providers indicate that their expectations are not met. On the contrary, the healthcare providers’ conducts reinforce their fear and apprehension and further strengthened their conviction that the service providers cannot be trusted and hence are discouraged for accessing the services. What is more problematic is the moral framework that guides the service provider’s conduct. The service provider upholds the same socially prescribed norms for girls and women’s sex and sexuality [in general all (unmarried)girls and women] and acts as the gate-keepers, taking up moral policing role in imposing conformity to the virtuous standards prescribed by the community. In addition to this, the healthcare providers, guided by their own deeply rooted prejudices against girls and women with disabilities; operates with the general notion that ‘girls and women with disabilities cannot and should not’ be engaged in sex and reproduction and hence does not/should not require SRH services” which leads to girls and women with disabilities considered to be not eligible and hence not entitled for the SRH services. These prejudices manifest itself in form of violation (abuse) and discrimination, thereby subjecting girls and women with disabilities to multiple layers of vulnerabilities and complexities in accessing SRH services.

Hence, girls and women with disabilities are apprehensive in accessing the available services for fear of disclosure, fear of being humiliated and fear of being abused. These barriers, in many ways, are similar to those faced by all adolescent girls and women in general but also indicates additional and multiple layers of vulnerabilities due to the added dimension of ‘disability’ and hence adding further complexities to the dynamics of exclusion in access to SRHR service.

Given these experiences, women and girls prioritize three key elements that define their acceptability of the SRH services, which constitute the parameters of “disability friendly SRHR services, which are:

1. Confidentiality
2. Dignified services
3. Safety

Therefore, for the services to be acceptable and hence “**disability friendly**” girls and women with disabilities expect full privacy and confidentiality; delivery of service with dignity recognizing them as rightful clients and in a safe environment. This focus is important for human rights-based approach, which calls for recognition of the user’s rights and sense of entitlement to the services as also emphasized by the ICPD, which recognizes that people’s sexual and reproductive health needs are rights that they are entitled to demand. The Privacy Act (2018) of Nepal also has provisions to ensure the right to privacy of the matters relating to body. The healthcare service providers need to ensure these key elements of ‘disability friendly SRH services’ for which “trust” is the key factor, lack of which contributes towards girls and women with disabilities’ unwillingness and hence barriers in accessing SRHR services.

8. CONCLUSION

Study results suggested that girls and women with disabilities, like all other girls and women, face barriers to accessing SRH services, but whose vulnerabilities are compounded by their disabilities. Disability adds to the complexity of exclusion by increasing vulnerability. As a result, ‘disability’ should be also included in the discourse of exclusion and accessibility for SRH services, in addition to gender and other forms of social marginalization. For girls and women with disabilities, the combination of gender prescribed roles and disabilities creates a unique set of barriers. This requires particular attention and comprehensive and nuanced understanding of interplay of disability and sexuality.

This study confirmed that availability and affordability are not sufficient for ensuring access to SRHR services. For girls and women with disabilities, acceptance is equally important, and even more so as it defines their willingness to access SRH services. The acceptability of services is largely determined by their life experiences, which are influenced by their social relationships and their interactions with the community and healthcare providers. It is imperative, therefore, to take into account the social narratives surrounding SRHR as well as the subsequent actions (conduct) of health care providers in delivering SRHR services when considering access to SRHR services for girls and women with disabilities. SRHR services are acceptable to adolescents and women with disabilities if they are provided with privacy, dignity, and safety. This call for conduct on the part of the health care providers should ensure that the elements are met through judgement-free, discrimination-free, and dignified services. As a result, it is evident that concerns for ‘dignity’ and ‘safety’ are key barriers to accessing “disability-friendly” SRHR services, particularly for girls and women with disabilities.

Way Forward: Implication for Prayatna Nepal

This study has been commissioned by Prayatna Nepal in order to contribute to the body of knowledge on sexual and reproductive health and rights of girls and women with disabilities. The understanding and evidence from the study is also expected to strengthen Prayatna Nepal’s SRHR

advocacy and programming. The key strategic priorities identified from this study, which is relevant for Prayatna Nepal includes:

1. **Expansion and more use of intersectional perspective (Disability, gender and SRHR):** Strongly promote the SRHR of girls and women with disabilities with focus on the complex (and unique) sets of barriers that they face due to the intersection of gender and disability emphasizing on the key messages that:
 - As all other girls and women without disabilities, girls and women with disabilities also face barriers in accessing SRH services, but with added layers of vulnerabilities due to disability. Hence, ‘Disability’ is an important dimension in the discourse of exclusion and access to SRH services in addition to gender and other forms of social marginalization and exclusion, and hence needs specific and specialized attention.
 - For ensuring access to SRH services for girls and women with disabilities, ensuring physical access and financial affordability will not suffice. ‘Acceptability’ of services is equally important and even more critical which defines their willingness to access the SRH services.
 - Confidentiality; dignity and safety are important parameters of service acceptability. For acceptability of services among girls and women with disabilities, in addition to the issue of privacy and confidentiality, which has been flagged out as a key barrier for all adolescent girls in general, the issue of ‘safety’ and ‘dignity’ should also be equally (and additionally) emphasized.
2. **SRHR, disability and human rights movement:** Ensuring SRHR of girls and women with disabilities would require mainstreaming this agenda not just within the SRHR movements but also concurrently within the larger human rights movements particularly women’s human right movement, social inclusion movement together with the disability rights movement whereby highlighting the intersection of disability, gender and SRHR. This would mean stronger collaboration with the OPDs, human rights institutions and other civil society organizations for advocacy and SRHR programming.
3. **Empowering through transformative pedagogy:** It would be useful for Prayatna to reach out to more adolescent and younger girls through its SRHR trainings. It would also be necessary to advocate for the review of the present school curriculum to ensure that it includes age appropriate SRHR education to young girls and adolescent with disabilities with content beyond just mensuration and contraception with focus on broader agenda such as sex, sexuality, autonomy and human right. Such interventions need to move beyond just technical or conceptual knowledge and focus on transformative pedagogies that would empower girls; build their critical consciousness to understand structural inequalities which is critical to help them transcend the dominant gender and disabilities narratives and thereby enable them to exercise their agency for actualizing their sexual and reproductive health and rights.
4. **Legal frameworks:** It is also important to engage with the government with regards to legal and policy framework for reproductive justice for girls and women with disabilities that honor their personhood; ensures their bodily autonomy; and strengthens their agency (with a specific focus on punitive measures in relation to privacy, confidentiality, safety and dignity in SRH services).

5. **Sensitive and accountable SRHR service providers:** It is also important to engage with the SRHR service providers (and institutions) through constructive dialogues and evidence-based advocacy that would enable them to reflect on their own prejudices in relation to gender and disability and how it creates barriers for adolescent girls and young women with disabilities in accessing SRH services. This may enable them to ensure that the services are inclusive, respectful and safe for everyone.
6. Evidence based advocacy and informed programming is the foundation of effective measures for SRHR for girls and women with disabilities. Given the context that SRHR of girls and women with disabilities under-researched, it is imperative to sustain the effort to continue in-depth inquiries in this subject matter with direct participation of girls and women with disabilities themselves. Some of the areas for future research includes
 - Further exploring the dynamics of each of the themes identified in this study, to understand the intricacies within it (barriers) - e.g., privacy confidentiality; safety; dignity etc.
 - Access to SRHR in relation to sexuality of women with disabilities
 - Intersectional inquiry on SRHR of women with disabilities (ethnicity/caste/race/religion/SOGI and other social identities to understand the intersectional discrimination and marginalization and multiple vulnerabilities and oppressions)

List of References

- Adhikari, K. P. (2019) *Realising the Rights of Persons with Disability in Nepal: Policy Perspectives*. Nepalese Journal of Development and Rural Studies, Volume 16 DOI: <https://doi.org/10.3126/njdrs.v16i0.3153>
- Bennett, L. (2006). *UNEQUAL CITIZENS: Gender, Caste and Ethnic Exclusion in Nepal*. The World Bank/UK Department for International Development (DFID)
- Bhattachan, K.B., Sunar, T.B., & Bhattachan (Gauchan), Y. K. (2009). *Caste-based Discrimination in Nepal*. Working Paper Series. Indian Institute of Dalit Studies, New Delhi
- Brunnberg, E. N., Bostrom, L.M, & Berglund, M. (2009). *Sexuality of 15/16-Year-Old Girls and Boys With and Without Modest Disabilities*. Sexuality and Disability. September 2009 DOI: 10.1007/s11195-009-9123-2
- Bucyibaruta, J.B., Peu, D., Bamford, L., & Van der Wath, A. (2019). *Closing the gaps in defining and conceptualizing acceptability of healthcare: A synthesis review and thematic content analysis*.
- Body and Data. (2020). *Beyond access: Women and queer persons with disabilities expressing self and exploring sexuality*
- Creating Resources for Empowerment in Action (CREA). (2012). *Count me IN! Research Report on Violence Against Disabled, Lesbian, and Sex-working Women in Bangladesh, India, and Nepal*
- Center for Research on Environment, Health and Population Activities (CREHPA). (2002). *Sexual risk behavior and risk perception among unwanted pregnancy and sexually transmitted infection among young factory workers in Nepal*
- Devkota, H.R., Kett, M., & Groce, N. (2019). *Societal attitude and behaviours towards women with disabilities in rural Nepal: pregnancy, childbirth and motherhood*. BMC Pregnancy Childbirth 19 (20) (2019). <https://doi.org/10.1186/s12884-019-2171-4>
- Donabedian, A. (2003): *An introduction to quality assurance in health care*, New York: Oxford University Press as cited in Dyer TA, Owens J, Robinson PGc(2016). The acceptability of healthcare: from satisfaction to trust. Community Dent Health 33(4):
- Brunnberg, E., Bostrom, M.L., & Berglund, M. (2009). Sexuality of 15/16-year-old girls and boys with and without modest disabilities, *Sexuality and Disability*, vol. 27(3) (September 2009).
- Gilson, L. (2018). *Acceptability, Trust and Equity*. In Mooney GM, editor. Cambridge: Cambridge University Press
- Gupta, J., Cardoso, L.F., Ferguson, G., et al. (2018). *Disability status, intimate partner violence and perceived social support among married women in three districts of the Terai region of Nepal*. BMJ Global Health. 3:e000934.
- Guttmacher Institute & A Galati A.J. (2015). *Onward to 2030: Sexual and Reproductive Health and Rights in the Context of the Sustainable Development Goals*. Guttmacher Policy Review, Volume 18, Issue 4 (<https://www.guttmacher.org/gpr/2015/10/onward-2030-sexual-and-reproductive-health-and-rights-context-sustainable-development>)
- Hameed, S., Maddams, A., Lowe H., et al. (2020). *From words to actions: systematic review*

- of interventions to promote sexual and reproductive health of persons with disabilities in low- and middle-income countries. BMJ Global Health;5:e002903. doi:10.1136/bmjgh-2020-002903*
- High-Level Task Force for the ICPD. (2013). *Policy Recommendations for the ICPD Beyond 2014: Sexual and Reproductive Health & Rights for All.* <http://www.icpdtaskforce.org/pdf/Beyond-2014/policy-recommendations-for-the-ICPD-beyond-2014.pdf>
- Higgins, A., Sharek, D., Nolan, M., Sheerin, B., Flanagan, P., Slaicuinaite, S., Mc Donnell, S. & Walsh H. (2012). *Mixed methods evaluation of an interdisciplinary sexuality education programme for staff working with people who have an acquired physical disability.* Journal of Advanced Nursing 68(11), 2559–2569.
- Holmes, R., Samuels, F., Ghimire, A., & Thewissen, S. (2018). *Nepal's cash allowances for children with disabilities.*
- IPPF Africa Region (nd). *Sustainable Development Goals and Sexual and Reproductive Health and Rights. What's in it for SRHR?* (<https://www.ippfar.org/sites/ippfar/files/2017-01/SDG%20E%20fn.pdf>)
- Kayastha, S. (2016). *Sexuality of women with physical disabilities: Experience and realities* [Masters dissertation, Tribhuvan University]. Tribhuvan University Library
- Liliane Foundations. (2019). *Paper on Position paper on Sexual and Reproductive Health and Rights of people with disabilities.*
- Morrison, J., Basnet, M., Budhathoki, B., Adhikari, D., Tumbahangphe, K., Manandhar, D., Costello, A., Groce, N. (2014) *Disabled women's maternal and newborn health care in rural Nepal: A qualitative study.* Midwifery. 30(11): 1132–1139 November 2014 doi: 10.1016/j.midw.2014.03.012
- Nepal Indigenous Disabled Association (NIDA), National Indigenous Disabled Women Association Nepal (NIDWAN); Asia Indigenous Peoples Pact (AIPP) (2018). *Nepal Reply from Indigenous Persons with Disabilities Organizations to the List of Issues in relation to the initial Report of Nepal Submitted to The Committee on the Rights of Persons with Disabilities 19th Session of CRPD Committee (14 Feb 2018- 9 March 2018)*
- Norwegian Agency for Development Cooperation (Norad). (2012). *Mainstreaming disability in the new development paradigm Evaluation of Norwegian support to promote the rights of persons with disabilities. Nepal country report.*
- Open Society Foundations. (2011). *Human Rights Watch, Women with Disabilities Australia and International Disability Alliance, Sterilization of women and girls with disabilities: a briefing paper* (November 2011). Available from www.opensocietyfoundations.org/publications/sterilization-women-and-girls-disabilities-0.
- Pandey, P.L., Seale, H., & Razee, H. (2019). *Exploring the factors impacting on access and acceptance of sexual and reproductive health services provided by adolescent-friendly health services in Nepal.* PLoS One. 2019 Aug 8;14(8):e0220855. doi: 10.1371/journal.pone.0220855. PMID: 31393927; PMCID: PMC6687105.

- Perrin, N., Marsh, M., Clough, A. et al. (2019). *Social norms and beliefs about gender based violence scale: a measure for use with gender based violence prevention programs in low-resource and humanitarian settings*. *Confl Health* 13, 6 <https://doi.org/10.1186/s13031-019-0189-x>
- Plan International, Norway. (2016). *Uncovered realities: Exploring experiences of child marriage of children with disabilities*
- Presler-Marshall, E. (2017). *Adolescent girls' capabilities in Nepal*
- Puri, M., Misra, G., & Hawkes, S. (2015). *Hidden voices: prevalence and risk factors for violence against women with disabilities in Nepal*. *BMC Public Health*, 15, 261. <http://doi.org/10.1186/s12889-015-1610-z>
- Sekhon, M., Cartwright, M., & Francis, J.J. (2017). *Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework*. *BMC Health Serv Res*. 2017 Jan 26;17(1):88. doi: 10.1186/s12913-017-2031-8. PMID: 28126032; PMCID: PMC5267473 <https://bmchealthservres.biomedcentral.com/track/pdf/10.1186/s12913-017-2031-8.pdf>
- Sexual Rights Initiative (SRI). (2018). *Submission to the Special Rapporteur on Rights of Persons with Disabilities on Right of Persons with Disabilities to the Highest Attainable Standard of Health*. March 2018
- Shrestha, S., & Wærdahl, R. (2020). *As Girls' access to adolescent friendly sexual and reproductive health services in Kaski, Nepal*. *Asia and the Pacific Policy Studies*. 7 (3)
- Simkhada, P.P., Shyangdan, D., Teijlingen, E. R. V., Kadel, S., Stephen, J., & Gurung, T. (2012). *Women's knowledge of and attitude towards disability in rural Nepal*. *Disability and Rehabilitation* 35 (7) July 2012 <https://doi.org/10.3109/09638288.2012.702847>
- The Danish Institute for Human Rights (DIHR). (2017). *AAAQ & Sexual and reproductive health and rights: International Indicators for Availability, Accessibility, Acceptability and Quality*
- The Institute of Development Studies (IDS). (2020). *Disability Inclusive Development. Nepal Situational Analysis June 2020 update*
- The New Humanitarian. (2014). *Why child marriage persists in Nepal*. Human Right Analysis. August 2014 <https://www.thenewhumanitarian.org/analysis/2014/08/15/why-child-marriage-persists-nepal>
- The Office of the High Commissioner for Human Rights (OHCHR). (n.d.). *Women's autonomy, equality and reproductive health. Working Group on discrimination against women and girls*. <https://www.ohchr.org/en/special-procedures/wg-women-and-girls/womens-autonomy-equality-and-reproductive-health>
- The Office of the High Commissioner for Human Rights (OHCHR). (n.d.). *Sexual and reproductive health rights. Special Rapporteur on the right to health*. <https://www.ohchr.org/en/special-procedures/sr-health/sexual-and-reproductive-health-rights>

- Tripathi,S. (2020). *Age of Marriage: Rights not Protection*. In plains peak (<https://www.tarshi.net/inplainspeak/age-of-marriage-rights-not-protection/>)
- United Nations Children Fund(Unicef). (2019). *Availability, Accessibility, Acceptability and Quality framework: A tool to identify potential barriers to accessing services in humanitarian settings* <https://gbvguidelines.org/wp/wp-content/uploads/2019/11/AAAQ-framework-Nov-2019-WEB.pdf>
- United Nations Population Fund (UNFPA). (2007). *Emerging issues: sexual and re productive health of persons with disabilities*. New York,
- United Nations Population Fund (UNFPA). (2013). *ICPD AND HUMAN RIGHTS: 20 years of advancing reproductive rights through UN treaty bodies and legal reform*
- United Nations Population Fund (UNFPA). (2017). *Population Situation Analysis of Nepal*
- Women with Disabilities Australia(WwDA). (2009). *Parenting Issues for Women with Disabilities in Australia' - A Policy Paper (May 2009)*.
- Women with Disabilities Network Nepal (13 disability rights groups across Nepal) (WwD Network) (2018). *Shadow Report submitted to the Committee on the Rights of Persons with Disabilities in its 19th session for the Country Review of the Federal Democratic Republic of Nepal 14 Feb - 9 March, 2018*
- World Health Organisation (WHO). (2011). *World report on disability*.
- World Health Organization (WHO). (2016). *Gender, equity and human rights: Availability, accessibility, acceptability, quality*

Annex 1: Participants Profile

S.N	Age		Marital status	Education	Currently living in Rental shared space (with friends)	Ethnic minority
1.	30	Blind	Unmarried	Bachelors	Rented shared space (friends)	No
2.	29	Blind	Married	Masters	Family (Husband)	No
3.	23	Blind	Unmarried	Bachelors	Kathmandu with parents	No
4.	24	Blind	Unmarried	Bachelors	Family (parents)	No
5.	28	Partially Sighted (low vision)	married	Bachelors	Family (parents)	Yes
6.	25	Blind	Married	Bachelors	Family (parents)	No
7.	24	Blind	Unmarried	Bachelors (second year)	Hostel	No
8.	25	Partially Sighted	unmarried	Masters in public administrative	Family (parents)	Yes
9.	26	Blind	Married	bachelors	Family (husband)	Yes
10.	23	Blind	Unmarried	BBA	Hostel	Yes
11.	21	Partially Sighted	Unmarried	BBA	Hostel	No
12.	20	Partially Sighted	Unmarried	BBA	Hostel	Yes