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Research and studies

Access to Sexual and Reproductive Health and Rights Information and Services

Perspectives of women and girls with disabilities in Uganda and Bangladesh

August 2021

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Executive summary

Overview

This research investigated the social barriers women and girls with disabilities face in accessing Sexual and Reproductive Health and Rights (SRHR) information and services in peri-urban and rural settings in Uganda and Bangladesh. The purpose of the research was to explore low access and uptake of SRHR information and services in these countries and identify and discuss the role of social and gender norms, barriers, and enablers in the health seeking behaviour of persons with disabilities.

A better understanding of these barriers will inform the design of inclusive SRHR programming, promoting the right to sexual and reproductive health for all.

Methods

Individual semi-structured interviews, focus group discussions, and observations involving a total of 80 individuals, including 47 women and girls with disabilities, were conducted. The research applied a thematic content analysis, combining deductive and inductive approaches that led to the organisation of findings on four main themes: Key Experiences and Perceptions of Women and Girls with Disabilities, Isolation and Communication Challenges, Future Perspectives and Sexuality, and Access to Related Information and Services.



Key Findings

To examine the factors that limit or enable women and girls with disabilities to access to SRHR information and services, the analysis and discussion of the findings focused on 4 main aspects: the role of the key gatekeepers, socially imposed barriers, the individual perceptions of women and girls, and enabling practices.

- The gathered testimonies in this research reveal a high prevalence of isolation and abuse, including sexual and gender-based violence (SGBV) amongst women and girls with disabilities.
- Dependency on the family is reinforced through a lack of independent accessible communication opportunities and self-selected social networks outside of the close family system.
- Family members play a key role as gatekeepers in promoting or obstructing the fulfilment of sexual rights.
- Opportunities to access SRHR information and services, and to take free decisions about sexuality and sexual health, are influenced by caretakers' and family members' perceptions and misconceptions about gender, age, disability, and sexuality.
- The impact of disability-based discrimination, stigma, and abuse against women and girls with disabilities on their self-efficacy is influenced by family interactions.
- The families' knowledge, beliefs, and the existence of support and information systems such as SRHR information are critical factors in the ability to resist restrictive social norms and social barriers.
- Education, economic opportunities, accessibility of services, and the exposure to social networks are determinant factors of whether a woman or a girl with disability accesses health and other related information and services.

Recommendations

Following this research, we recommend the following programmatic interventions for the successful delivery of SRH information and services to women and girls with disabilities:

Key gatekeepers

- Strengthen the knowledge of key gatekeepers about SRHR of women and girls with disabilities with particular attention on their right to informed consent, make informed choices and bodily autonomy.
- Support parents and caretakers, including grandparents, in their role as key gatekeepers. Help them to offer guidance on the options available, to promote self-reliance and to empower girls with disabilities.
- Address the high risk of SGBV against women and girls with disabilities with key gatekeepers and SRHR actors, including providing awareness sessions and training modules on GBV and disability for health workers.

Reduce socially imposed barriers

- In co-cooperation with Organisations of Persons with Disabilities (OPDs) and SRHR stakeholders, develop strategies that focus on addressing restrictive social norms and misconceptions of disability through Social Behaviour Change and Communication strategies.
- Improve communication opportunities and social networks of women and girls with disabilities through an holistic approach that includes; interventions focusing on reducing dependencies of women and girls with disabilities on their family members, facilitating access to education and income generating opportunities.

Positive impact on perception

- Recruit women with disabilities as community health workers and provide reasonable adjustments that allow them to do their job, such as lowering desks for wheelchair users. Portray their participation as experts in domains that are socially relevant.
- Encourage the inclusion of women with disabilities into existing women's peer groups and address issues related to SRHR that incentivise and inspire their support to other women with disabilities.
- Design SRHR information materials together with women and girls with disabilities to better reflect their lived experience.

Enabling practices

- Ensure the participation of women and girls with disabilities and their family members in the design, implementation, monitoring and evaluation of health programmes targeting male family members (i.e. fathers, brothers, and husbands), and female caregivers of all ages.
- Design inclusive outreach strategies and referral mechanisms that take into full consideration the barriers women and girls with disabilities experience in accessing services.
- Encourage open forums for the discussion and dissemination of good practices amongst health care workers, where women and girls with disabilities or OPDs can participate and contribute.

Introduction

Over 1 billion people worldwide, around 15% of the world's population, are estimated to live with some form of disability. According to WHO, this number is increasing (WHO, 2011) (WHO, 2020). Due to a negative interrelation between disability, education, and economic opportunities, persons with disabilities often live in hard-to-reach communities and are disproportionately affected by extreme poverty. Strong evidence from literature and practice shows that the sexual and reproductive health rights and needs of persons with disabilities, especially those who are most vulnerable due to poverty, continue to be largely unmet (WHO, 2011).

The aspirations, priorities, and concerns of many persons with disabilities about their sexual and reproductive health continue to be disregarded by caregivers, family members, communities, and health service providers. Additionally, social norms limit their sexuality, personal choices, and rights at many different levels – personal, interpersonal, and social. These societal stigmas and cultural stereotypes, rejections, and human rights violations have created barriers, preventing the fulfilment of the sexual and reproductive health and rights of persons with disabilities, and contributing to the misconception that they do not have the same right to sexuality, partnerships, and parenthood. This also increases the vulnerability of persons with disabilities to abuse (WHO, 2011).



Introduction to the project

WISH2ACTION, a Foreign, Commonwealth & Development Office (FCDO) 3-year funded project (2018-2021) is being implemented by a consortium of 6 international organisations to deliver 16.921m Couple Years of Protection (CYP), with 2.2m additional users. The consortia partners are operating in 16 low and middle-income countries in Asia and Africa, with a mandate of ensuring that the project interventions and services are inclusive and equally accessible by all people, including persons with disabilities.

Under the scope of the WISH (Women's Integrated Sexual Health) Project, an Evidence Gap Map (EGM) analysis was undertaken. The results show that across all outcome areas, there is a low amount of evidence in relation to 'what works' to ensure persons with disabilities have access to SRH services in lower and middle-income countries.

In order to address this gap and contribute to the existing body of evidence, Humanity & Inclusion (HI) has initiated this research to better understand the factors, enablers, drivers, and patterns of access for women and girls with disabilities to SRH. The findings and understandings, in the local context of the two selected countries, Bangladesh and Uganda, aim to deepen the understanding of factors for exclusion and encourage enabling practices towards inclusion.

ThinkPlace, a Kenya-based consultancy in strategic and service design, carried out this qualitative research on behalf of HI and in liaison with HI's in-country partners, as well as the Organisations of Persons with Disabilities (OPDs) that cooperated on the WISH2ACTION project. The research was carried out in four research sites in the selected countries and will help plan for SRHR social and behaviour change campaigns in the scope of SRHR inclusive service provision. More broadly, the research will guide actors working in SRHR service delivery and communication, advocacy, and cooperation with OPDs.

Objectives

The overall objective of this research was to contribute to existing literature and increase the understanding of the institutional, cultural, or personal barriers, constraints and resistances that prevent women and girls with disabilities from accessing SRHR information and services.

Background

Understanding health seeking behaviour and access to healthcare services requires a systemic perspective on the factors that lead to or hinder an individual or group to seek medical care. These factors are related to the supply-side characteristics of the healthcare system, as well as the demand-side, defined as the ability of individuals to perceive, actively seek, reach, pay, and engage with health services (Levesque, Harris, & Russell, 2013).

Despite the evidence demonstrating that sexual desire, activity, and need for SRHR services among women with disabilities are comparable to those for women without disabilities (Ganle, 2020), numerous barriers exist at national, institutional, individual, community, and economic levels that hinder women and girls from accessing services. Studies carried out in low and middle-income countries, where most healthcare systems are greatly under resourced and underdeveloped, reveal how women and girls with disabilities also face additional challenges to access to SRHR services (Rohwerder, 2018).

The existing literature on sexual and reproductive health and persons with disabilities in low and middle-income countries is limited in scope (Mark T. Carew S., 2017) (Chappell P. &, 2019) (Hughes K, 2012). The available research mainly provides insight and information into a variety of physical barriers to accessing SRH care at medical facilities (Gamle, et al., 2016) (Nampewo, 2017), as well as negative experiences resulting from communication problems or discriminatory practices of health providers that make it hard for women and girls with disabilities to trust and see value in SRHR services (Peta, 2017) (Mprah, 2017) (Jonas, 2017) (Aresu, 2019) (Dean, Tolhurst, Khanna, & Jehan, 2017) (Rugoho, 2017) (Begum, 2020) (Khandaker M, 2018) (UN Department of Economic and Social Affairs, 2018). Additionally, given that sexuality often remains a taboo subject, as well as the misconceptions associated with poor knowledge and limited exposure to positive social norms, studies have shown how family protection and restrictions around decision making lead to a lack

of respect for the agency of women and girls with disabilities (Burke, Kebe, Flink, van Reeuwijk, & le May, 2017) (Hasan T, 2014) (Aresu, 2019).

The present research in the field of the SRHR of women and girls with disabilities is greatly focused on knowledge and awareness of SRHR care, as well as the appropriateness of services for women and girls with disabilities. Whereas some studies report lack of self-esteem (Ganle, 2020) (Renu Addlakha, 2017), there are less references to women and girls' own awareness of sexual and reproductive self-efficacy and rights, the psychological impact that the aforementioned barriers have, and the related coping mechanisms across different disabilities.

Uganda context

In Uganda, according to the latest, and likely outdated population census, the percentage of persons with disabilities is 12.9% (Uganda Bureau of Statistics, 2014) – approximately 4.5 million persons. This percentage disproportionately affects women and is higher in urban areas than in rural settings. Persons with disabilities are amongst the most neglected in the country, with the majority facing economic, political, and social barriers that negatively impact their physical, economic, and social well-being (Kaggya, October 2019).

Uganda's Maternal Mortality Rate (MMR) is one of the highest in the world, with 375 deaths per 100,000 live births (World Bank, 2017). There is abundant evidence of the discrimination and stigma experienced by women and girls living with sexually transmitted infections (STIs) and the difficulties women and girls face to access quality SRH services, including those dedicated to survivors of SGBV (CEHURD, 2016) (Guttmacher Institute, 2019).

In recent literature, including the 2018 Lancet Commission publication, the access challenges women and girls with disabilities experience are specifically addressed, including the lack of adapted infrastructures and accessible information in general services (from school to healthcare), ingrained discrimination, and misconceptions about disability that are passed on by communities and health providers themselves (Ochom, 2014) (Ahumuza, 2014). Misconceptions include the belief that women with disabilities are asexual, cannot make decisions about their reproductive health, and do not need SRHR information. These sustained fallacies lead to isolation, reduced self-esteem, and increased risk of physical and sexual violence (Kaggya, 2019).

Uganda is also home to the highest number of refugees in Africa, hosting around 1.45m refugees from different conflict affected neighbouring countries



(UNHCR, 2021). According to the National Union of Women with Disabilities of Uganda, refugee women and girls with disabilities experience additional discrimination because they are often excluded from networks and advocacy initiatives (Betty, 2019). This discrimination, particularly against adolescent girls with disabilities, may increase their exposure to various forms of violence, including gender-based violence (Women's Refugee Commission, 2014).

Bangladesh context

In Bangladesh, it is estimated that approximately 10% of the population, or 164m people, live with a disability (Centre for Disability in Development, 2021). In 2015, The National Council of Disabled Women (NCDW), in collaboration with National Grassroots Disability Organisation (NGDO) and Bangladesh Legal Aid and Services Trust (BLAST) worked on a report analysing the status of the implementation of the CRPD (Convention on the Rights of Persons with Disabilities, 2010) in Bangladesh (NATIONAL COALITION PARTNERS, 2015). The report identifies various barriers that persons

with disabilities face in the country and shows how these barriers affect their ability to exercise their basic rights, including access to non-discriminatory justice, freedom, transport, mobile/internet services, and various services related to healthcare. In addition to access issues, inequality in employment conditions and women's exclusion from financial autonomy worsens the negative, negligent, and insensitive attitudes to disability amongst community members (Almeida, 2021).

People in Bangladesh generally have low levels of SRHR knowledge and limited access to information and services. For adolescents, taboos and traditional norms lead to limited negotiation skills, high rates of early pregnancy, STIs, sexual violence, forced marriage and high fertility rates (MCH Services Unit, 2016). Women with disabilities in Bangladesh face grave barriers to their reproductive rights and health as they are more stigmatised, making them vulnerable to higher incidences of intimate partner violence and abuse by close family members (Ando, 2017) (UNICEF Bangladesh, 2014).

Methodology

This research used qualitative and ethnographic research methods to investigate the behavioural drivers and access barriers of women and girls with disabilities, and those of other individuals that influence them, including family members, caregivers, and peers. Lines of inquiry were informed by a literature review on disability and SRHR in Bangladesh and Uganda. Methods included in-depth interviews and, where possible, interactive activities. Due to COVID-19 restrictions, ethnographic observations were not conducted, as originally planned. Additionally, 20 out of the 40 interviews in Bangladesh were conducted through remote methods due to a national lockdown. Informed by the literature, this research followed an iterative line of enquiry, guided by the following research questions:

1. Who are the **key gatekeepers** who prevent, limit, or enable women and girls with disabilities to access SRHR information and services?
2. What are the **socially-imposed barriers** that lead to poor health seeking behaviour and prevent women and girls with disabilities from accessing SRHR information and services?
3. How do these barriers affect **the individual perceptions and sexual and reproductive lives of women and girls with disabilities**?
4. What are the **enabling practices and beliefs** that contribute to women and girls' access to SRHR information and services?

Each research week included a cycle of four days of immersive research, with in-field rapid synthesis occurring on the fifth day. These rapid synthesis sessions reviewed emerging patterns and areas for further inquiry, informing the refinement of the lines of inquiry and areas of focus for the following week.

To explore different areas of focus during in-depth interviews, the researchers selected from a set of tools, including card sorting (group individual images on cards according to criteria that make sense to them), scenarios (scripts of short events that prompted participants to react and make suggestions) and perceived activity (visual prompts to uncover participants' subjective interpretations and implicit associations).

Adaptations

To conduct inclusive research, the researchers adapted the planned methods and tools to adjust to the needs of individual participants and ensure accessibility and meaningful participation. For example, interviews were carried out with support from sign language interpreters and tools were modified through the use of simple language that was reviewed by HI, ensuring the lines of inquiry were understood by all participants - particularly persons with cognitive disabilities, but also by persons with a low literacy level (with and without a disability). For persons with cognitive disabilities, the sessions were interactive and appropriately paced, enabling effective communication between the researcher and participant.

Prior to the start of an interview, the researcher discussed and defined key concepts with participants, particularly those related to SRHR. Additionally, image-based tools were used in parallel during interviews to help explain questions and facilitate discussion about topics that could be perceived as sensitive, such as sexual relations before marriage. All image-based tools were accompanied by a description that could be read out to those with visual disabilities.

To build trust and uncover deeper behavioural insights about the primary audience, the researchers offered participants the opportunity for follow-up interviews where needed. Second interviews were also important for participants who needed additional time to share their views and opinions, e.g., participants who felt tired from the interaction or participants with hearing disabilities who required sign language interpretation.



Research Team

Due to COVID-19 travel restrictions, the research team composition differed between the two countries, Uganda and Bangladesh. In Uganda, field research was led by two ThinkPlace researchers (one from Uganda and one from Kenya). The researchers worked alongside two translators/research assistants (one from each region, who had experience conducting similar research), two mobilisers (one from each region, who were members of an OPD), and one sign language interpreter.

In Bangladesh, the field research was led by Key Makers Consulting Ltd., a local research firm based in Dhaka. The research was led by four researchers (two from each region), four mobilisers (two from each region, including one member of an OPD), two translators (who were only used in Chattogram), and one sign language interpreter.

Both field teams were supported and guided by lead investigators from ThinkPlace, with academic qualitative research experience.

In both countries, all team members involved in the research participated in a one-day disability inclusion training session and a one-day workshop on the research objectives and approach, consent processes, and referral mechanisms. Research assistants and mobilisers also pre-tested the tools used to adapt the language to the local context.

Study Population and Setting

This research involved women and girls with varying disabilities from three different age groups (15-19, 20-29 and 30-49), statuses (marital, refugee, education) and locations as the primary target group, with the aim of exploring how different factors and intersecting vulnerabilities influence their access to SRHR information and services. Since the primary target audience included adolescent girls with disabilities, specific informed consent measures were undertaken.

As a secondary target group, the research targeted influencers of access to SRHR, i.e., family members, individuals engaged in the provision of SRH information and services (doctors, nurses, community health workers in public and private facilities), and community leaders and gatekeepers, including religious and education leaders and members of OPDs and other civil society groups. Men were included as a secondary target audience to ensure that their perspective was included, as they were not involved in the direct interviews. The detailed description of the study population can be found in the table below.

Uganda

24 women



50% of the women are from Yumbe (rural setting)

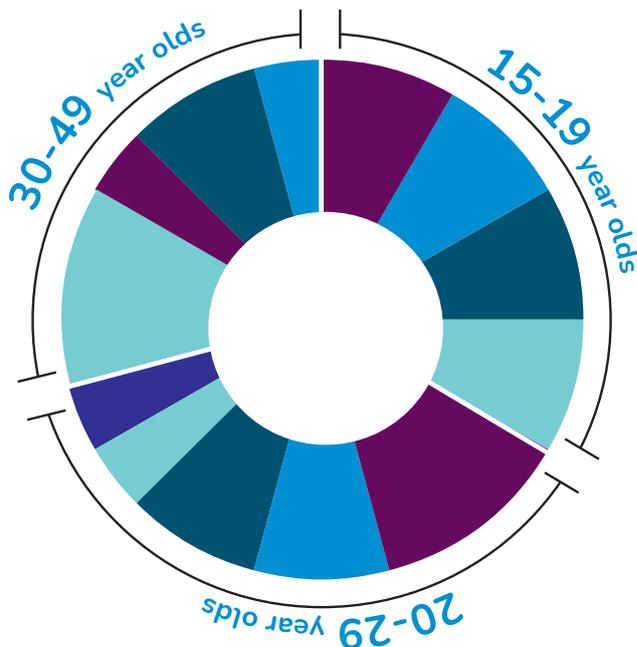
50% of the women are from Arua (peri-urban setting)



15 experienced being in relationships:



- 6 married
- 3 in an unmarried relationship
- 6 divorced
- 12 had children



- Hearing disability
- Cognitive disability
- Mobility disability
- Visual disability
- Cognitive and mobility disability

Bangladesh

23 women



50% of the women are from Chattogram* (urban setting)

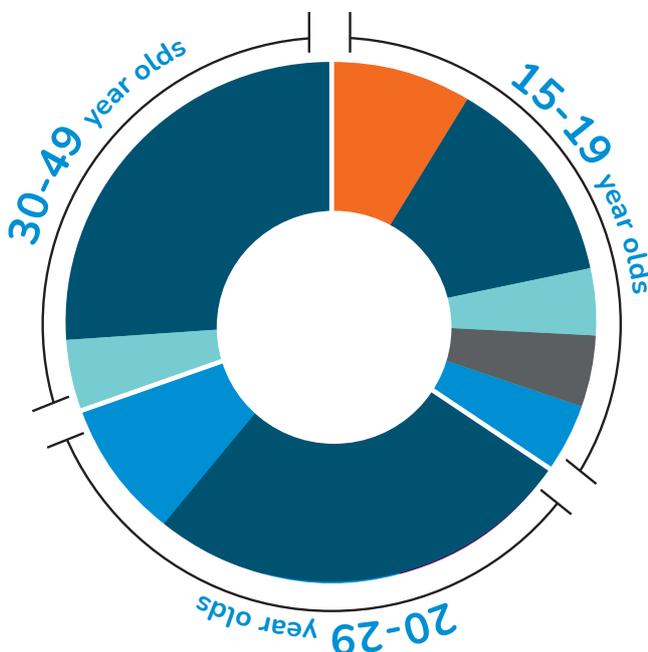
50% of the women are from Kurigram (rural setting)



9 experienced being in relationships:



- 7 married
- 2 separated or divorced
- 7 had children



- Cognitive and visual disability
- Cognitive disability
- Mobility or physical disability
- Visual disability
- Visual and mobility disability

Data Collection

Sampling

Research participants were selected based on pre-established demographic criteria. Women and girls with disabilities were selected based on age, sex, and refugee status and divided into groups with visual, physical, cognitive, and hearing disabilities. The majority of the participants had no or limited experience in accessing SRHR services. Users of services provided by the project partners through the WISH project were not included in this research, to ensure there was no bias in the data collected.

Recruitment

One week prior to data collection, selected mobilisers attained local approvals to inform key gatekeepers of the upcoming qualitative research and the intention to contact the various study populations. The research teams and mobilisers also met with OPD partners in all four research sites to establish networks of trust within the community prior to the start of recruitment. Through these connections, mobilisers identified participants using pre-established demographic criteria. The research deployed the snowball sampling technique through the help of OPDs in the community. Mobilisers identified participants with disabilities who were either currently involved in OPD activities, or who were already accessing SRH services, to help recruit other research participants.

During recruitment, mobilisers asked participants about any visual, hearing, communicating, mobility, and/or self-care difficulties using the Washington Group Short Set on Functioning (WG-SS). This helped inform mobilisers and researchers about the disabilities of each participant, allowing them to make the necessary adaptations to interview guides and locations and ensure appropriate accommodation.

Ethics and Safeguarding

This research was carried out with Ethical Approvals received by the Institutional Review Board (IRB) at the Institute of Health Economics, the University of Dhaka in Bangladesh, the Research Ethics Committee at The Aids Support Organisation (TASO) in Uganda, and the Uganda National Council for Science and Technology (UNCST).

All research activities strictly followed the approved ethical protocols and referred to international ethics standards, such as the WHO guidelines on research into sexual and gender-based violence and protection of children to ensure confidentiality, confidential data management, and the protection and safeguarding of interviewed and involved persons (WHO, 2007). The researchers and support team were mandated to review and sign all HI safeguarding policies and code of conduct to ensure safeguarding procedures.

Informed Consent

In accordance with the ethical protocol, informed consent was obtained prior to participants entering the research. Informed consent was collected by mobilisers from potential participants in their local language in two stages. The first stage included giving information to the participants and allowing them to reflect on the information, ensuring they felt no pressure to respond to the researcher immediately. In the second stage, the mobiliser reiterating the terms of the research, according to the points outlined in the consent forms. Following this, participants consented to each term and gave explicit consent before agreeing to take part in the project.

The research put in place mechanisms to protect both minors and participants with low literacy. These participants may not have been able to read the informed consent form, so research team members were trained to guide them through it, providing all the information in the form in simple terms, in the local languages and/or sign language. For participants with visual disabilities, consent forms were printed in large font and, when needed, verbal consent was sought.

In the case of minors (15-17 years old), two levels of informed consent were sought, from the participant and the parent. Additionally, to ensure safe participation, the research team ensured that minors were never interviewed alone by a member of the research team and that a second member of the team was present, as an observer. Minors were informed that they could have a parent, guardian, or friend of their choice accompanying them during the research

activity, if they wished. In Bangladesh, there were three instances where the mother or sister-in-law of an adolescent participant was present during the interview, which created potential bias in responses about more intimate topics.

Many of the primary target audience participants were accompanied by a personal aide. Prior to starting the interview, the team explained the flow of the interview to the personal care aide. The participant was then asked to give consent if the personal aide was to be present during the interview. If necessary, the researcher took the aide through the questions to build trust prior to starting the interview.

COVID-19 Prevention Measures

To minimise the risk of COVID-19 transmission amongst the participants and the research team, all protection measures were implemented in accordance with national and international requirements. These included: the use of protective masks and/or face shields by researchers, participants, and their aids and community mobilisers, social distancing, and the choice of an outdoors environment to carry out the interviews.

Other Ethical Considerations

Researchers implemented safeguarding measures, which included the protection of participants' personal information through non-identifiable IDs and disclosing information only where legally and ethically appropriate. Interviews were conducted in safe locations with audio/visual privacy, where the participant felt comfortable to speak. Participants were referred to health services and psychosocial support if they had experienced violence or requested more information.

Limitations

The initial research design targeted non-users of SRHR services in order to ensure that the most marginalised and hardest to reach women and girls were included in the study. While the research team achieved the desired sample size, not all participants were 'non-users' of SRHR services and not all types of disabilities were equally represented. In Uganda, the refugee settlements were arranged in a way that made it difficult to reach participants with physical disabilities. In Bangladesh, a COVID-19 nationwide lockdown prevented the team from conducting face-to-face interviews, so all the interviews for Chattogram were conducted virtually, through Zoom. As a result, only participants with access to strong internet connectivity were selected. Persons with hearing disabilities were not represented due to challenges with video lag time that hinders lip-reading and sign language interpretation. The visual materials created for the interactive activities were not used during these online interviews.

Interpretation bias may have occurred in Uganda, where some of the refugee participants spoke a local language unknown to the research team, and peers or family members translated on behalf of the participants. Additionally, lines of inquiry were shortened and simplified when a participant with a hearing disability only knew a form of sign language spoken with a family member in their household.

Social desirability bias was present, especially in Bangladesh when younger participants were asked to discuss self-reported behaviour towards relationships and sexual activity in the presence of their mother or sister-in-law (3 out of the 5 minors interviewed). Additionally, COVID-19 movement restrictions prevented teams from conducting observational interviews and holding interviews privately, away from households. The teams were trained in different tactics and tools to approach topics that could be perceived as sensitive by the participants through storytelling and indirect lines of inquiry.



Data Analysis and Main Themes

All interviews were recorded, translated, and transcribed. While in the field, the research team conducted daily and weekly synthesis sessions to analyse the findings and begin deriving key themes. During these sessions, the field team compared field notes, rapidly identified key patterns and themes, and developed an overall picture of participants' feedback and experiences as reported by them. Once researchers returned from the field, ThinkPlace, together with the local research partner Key Makers (in Bangladesh) conducted a series of highly interactive workshops to further analyse and synthesise the data from multiple sources, producing affinity diagrams from session notes and participant quotes. This exercise is mostly focused on identifying behaviour patterns, commonalities, and divergences between the types of disability and age.

The following four themes emerged from this research and capture the insights that were gathered about user needs, desires, and concerns in familial, educational, professional, community, and health contexts.

- 1. Key experiences and perceptions of women and girls with disabilities:** this theme encompasses findings about the life conditions of women and girls with disabilities, their relationship with family members and others in society, and their aspirations, role models, and perceptions of self.
- 2. Isolation and communication challenges:** this theme describes the implications of certain circumstances and events that women and girls with different types of disabilities experience in their lives.
- 3. Future perspectives:** this theme relates to different aspects of the social lives of women and girls with disabilities with future perspectives that increase their social capital
- 4. Sexuality and access to relevant information and services:** this theme includes findings related to the specific experiences of women and girls with disabilities with the health system, health providers, and facilities.

Following the production of two field research reports, the research teams organised one reflection workshop and analysis of the insights, looking transversely across the themes into common and different barriers and enablers to access SHRH information and services.

Findings



Uganda Findings

1. Key experiences and perceptions of women and girls with disabilities

This research showed that women and girls with disabilities are often given limited to no opportunities to acknowledge or develop their agency. Their gender, intersecting with factors such as age and disability, determined what their families expected them to do, and the role they should play in their community.

Women and girls with disabilities who were interviewed described low self-esteem, especially regarding their roles and aspirations in the community. They did not doubt their capability to clean or work, but they clearly expressed insecurity about their ability to meet the gendered expectations and standards of the society in which they lived. Most reported that the aspirations of the women and girls with disabilities were to support their family economically and to have children.

Despite expressing a clear interest in having children, most interviewed women and girls with disabilities did not anticipate a future where comprehensive SRHR information or services were relevant. This is possibly because many did not have access to information about existing services, did not have the choice to decide on when and how often to have children, and could not access services independently. Some reported negative experiences at facilities, such as judgemental and discriminatory attitudes from health workers. Many women did not consider the health support (maternal and antenatal care) that mothers with disabilities receive as part of SRHR, or they considered SRHR services as something that was not for them.



“When I was in school, the children would call me bad and mad and I would beat them. I don’t want to go back to school because people will insult me and say I have a sickness which will make me ashamed.”

-Young refugee girl with cognitive disability from Yumbe, Uganda

According to the research participants, both in Arua (predominantly Christian) and in Yumbe (predominantly Muslim), women and girls with cognitive disabilities, and those who experience difficulty carrying out physical activities as result of their disability, are generally subject to ill treatment and discrimination due to myths and misconceptions. Persons with cognitive disabilities are regarded as contagious or as having a curse or punishment that is transferable to their own children. Persons with physical disabilities from birth are thought to only be able to deliver children with the same physical impairment.

These misconceptions are passed on through negative attitudes in the community. However, they were not shared by the girls or women themselves. Some of the interviewed women and girls with disabilities mentioned that they were affected by the shame and fear imposed by these misconceptions, especially when they were aggressively verbalised to them.

2. Isolation and communication challenges



“Children with disability are left to sit at home like guards, they can’t do much.”

- Community leader from Arua, Uganda.

It was found during this research that women and girls with disabilities had limited social interactions with members of their community outside of their household. These social interactions were sporadic, especially for the participants who did not work or attend school. For example, one interviewee talked about unplanned visits from neighbours or relatives. One interviewed girl with a cognitive disability was visited by a young peer for company. While at home, most of the interviewed women and girls with cognitive or auditory disabilities were not actively engaged in conversations with those living with them, but instead were addressed only regarding their house chores.

Of the 24 interviewed women and girls with disabilities living in Uganda, the 2 girls and 3 women with cognitive disabilities reported that interacting with others was very challenging for them. As a result, they opted mostly to stay home. Those with hearing disabilities expressed frustration about growing up unable to communicate with their families apart from limited gestures. However, of the 4 girls with auditory and visual disabilities, the two who attended an inclusive school reported having aids or a family member, usually a mother or sister, who acted as guide for interactions with others outside the household. The two girls with physical disabilities also received assistance from family members (siblings, uncles, parents), but mentioned a lack of means, unwillingness of others to provide assistance, and a lack of mechanical aids such as a wheelchair as barriers to interacting with others outside the family.

In Uganda’s refugee camp in Yumbe, the condition of isolation and difficulty in communication for women and girls with disabilities in this research was exacerbated by language barriers and the lack of social cohesion amongst displaced families.



“I have no friends, no one loves me”

- Young woman with cognitive disability from Yumbe, Uganda

In Arua, most women and girls with disabilities and their families had access to radio, newspapers, and mobile phones. This enabled them to access information and entertainment. Although all research participants or their families had access to mobile phones, very few women or girls with disabilities had personal phones.



“My uncle drinks a lot and whenever he gets upset, he beats me.”

- Girl with cognitive disability from Arua, Uganda

In the literature, exclusion and isolation is described as a risk factor to violence and SGBV (UNFPA 2018). Three of the 24 women and girls with disabilities shared their experience of abuse by strangers, as well as family members from within the household. Two of these girls have a cognitive disability, and one a hearing disability.

In all three cases, the abuse was directly reported to and acted upon by the police which, based on data from international research, rarely happens. The decision of what to do in such cases was taken by a female caretaker with authority, such as an aunt or grandmother. The women and girls with disabilities interviewed in this research did not refer to themselves as being in charge of the decision to seek medical or psychological care for themselves.

Prior to marriage, women and girls with disabilities are often led by their families to have relationships that may increase their chances of marrying, or improve their sexual preparedness, but this potentially exposes them to abuse. In these cases, families proactively seek male partners who may potentially become their daughter’s spouse.

3. Future perspectives

In Uganda, most interviewed women and girls with disabilities were in school or had an income generating activity. Schools, NGOs, and OPDs were described as a source of inspiration for women and girls with disabilities.

Amongst the research participants, for those involved in an income generating activity, the underlying motivation to work was to help their family financially and meet family expectations. Despite significant challenges, half of the interviewed refugees owned a small business or income generating activity. Refugees with disabilities had an increased exposure to these activities, possibly due to the presence of NGOs in the refugee camp setting who facilitate the organisation of support groups, such as vocational support and start capital.

Attending school was very important and highly valued by the participants. Nevertheless, many reported significant challenges in commuting or attending school as this is where events of insult and discrimination frequently occurred. Many women and girls with disabilities who were interviewed said that they were prepared to cope and tolerate these events in order to attend school.

Girls with physical and cognitive disabilities were less likely to attend school due to the schools' inability to adapt to their specific needs, such as help to commute to school, or appropriate learning support.

For those with hearing disabilities, learning sign language while attending school became so important that in some cases, their connection with their teacher and sign language speaking peers was reported to be stronger than the one a child has with their parents.

Greater access to education increases the chance to receive information, as well as raise awareness about SRHR and promote the confidence to realise these rights.

Most OPDs in the research area only catered to visual or hearing disabilities, which excluded women and girls with cognitive and other disabilities from participating. Eight older participants were members of a group or association of persons with disabilities. These participants mentioned how they appreciated the groups and associations, primarily for the companionship and learnings on financial sustainability and economic empowerment.



“We are creating a savings group that includes women with and without disabilities. This is a form of integrating women with disabilities who are isolated at home, back in the society, giving them a sense of belonging and offering them financial support.”

- OPD member from Yumbe, Uganda.

In Uganda, organised civic groups, savings groups in the majority, are very common. Associations of persons with disabilities that do the same are therefore trusted and appreciated. One of the interviewed OPD leaders mentioned that their savings groups follow inclusive approaches by addressing women and girls with disabilities, caregivers, and all other women, with the aim of encouraging social interactions through participation in these activities. These interactions have the potential to increase self-esteem and self-reliance.

4. Sexuality and access to relevant information and services

Most interviewed women above 18 years old with disabilities have accessed some form of health service in the past. Amongst the services mentioned, 9 women and girls with disabilities in Arua accessed SRHR related services, including HIV testing, family planning, or treatment following sexual abuse. Seven women and girls with disabilities in Yumbe, all of whom had children, had attended at least one antenatal care session, whereas in Arua, only 1 of 4 women with children had accessed antenatal care.



“If my sister falls sick, I call a motorcycle driver to help me take her to the hospital. Because he is my friend, I can pay him later.”

- Brother of girl with mobility disability from Yumbe, Uganda

It is important to note that, most often, accessing these services was the result of the initiative of family members or partners of women and girls with disabilities. Overall, family members and partners were shown to be very influential in determining when, where, and how often women and girls with disabilities participating in this research sought health services.

According to interviewed health professionals, women and girls with cognitive disabilities are highly restricted from leaving the house because their families fear their exposure to possible sexual abuse. They reported that it is common for older female family members, usually an aunt or grandmother, to bring a girl with a cognitive disability to the health facility with a particular request for long-term family planning methods, since this is seen as an effective measure to avoid pregnancies in the event that they are sexually abused.

Sexual violence was also mentioned as the main reason that many families allow access to HIV testing for girls with disabilities. In Uganda, the need for HIV testing of sexually active individuals has been successfully promoted, but many other priorities have not gained the same recognition. Therefore, additional care in response to sexual violence, such as emergency contraception, safe abortion counselling, and treatment for STIs, will only be accessed if healthcare providers successfully convince the family to do so. Research participants

reported that health facilities are characterised by poor accessibility, both in terms of physical infrastructure, as well as negative experiences.



“If the personal aid of a woman with disabilities does not bring her to our outreach clinic, there is nothing I can do.”

- Health worker from Arua, Uganda

Healthcare professionals reported having no formal training to meet the communication needs of a woman or girl with disabilities, such as using sign language to communicate or using simplified language for persons with cognitive disabilities. This resulted in communication difficulties and had an impact in the exercise of informed consent of girls and women with disabilities who were often excluded by family members in decision making.



“Sometimes I crawl because the places in the clinic are not accessible.”

- 26-year-old woman with mobility difficulties from Yumbe,

Uganda Some women or girls with disabilities were interested in SRHR services, but often ended up being excluded from access to information due to a lack of accessible SRHR information for them or their families. Women also reported facing physical barriers to accessing services. The lack of direct communication between health providers and girls and women with disabilities resulted in a distance between them.



Bangladesh Findings

1. Key experiences and perceptions of women and girls with disabilities



“All her brothers and sisters are educated but she is not. We will have to take care of her for years to come.”

- Brother of a young woman with hearing disability from Chattogram, Bangladesh

In Bangladesh, this research showed that women and girls with disabilities were considered unequal amongst family members in terms of capabilities. Some parents and siblings considered girls and women with disabilities to be a ‘burden’ as the person was unable to earn, leaving them reliant on family support. They were described as holding back the family’s progress. In fact, 6 out of 8 of the family members interviewed used terms like ‘burden,’ ‘dependent,’ or ‘unable’ when referring to the girl or woman with disability in their family. Furthermore, 2 women with disabilities reported that their brothers mistreated them and hit them during arguments.



“Some of the boys and girls disturb us when we go to school. When boys in the street disturb me while going to school, I curse them so that they stop.”

- Young woman with a physical disability from Kurigram, Bangladesh



“[My husband] is very fair and handsome. But I’m not good looking. I am boring.”

- Woman with a physical disability from Kurigram, Bangladesh

The reported self-esteem of the participating women and girls with disabilities was extremely low – at times they seemed to assume responsibility for the abuse experienced or expressed guilt for being a burden for the family. Many had internalised their lack of self-reliance in all aspects of life.



“I know a disabled student. She was a minor. She was married off to an insane man. They took 30,000 taka for dowry.”

- Teacher from Kurigram, Bangladesh

Dowry practices in Bangladesh determine that the family of a woman or girl must pay a compensation to a man's family, whereas sons are considered 'assets' as they bring wealth into the family. It was confirmed in this research that, in this context, a daughter with a disability can be seen as an additional burden since her marriage comes at a higher cost to her family.



“They call us ‘abnormal’ and when we walk on the road, these normal people call us names and throw things at us.”

– Woman with physical disability from Kurigram, Bangladesh

The birth of a child with disabilities can result in stigmatisation of the child and parents, as the social behaviour and norms of communities is often based on misconceptions and myths related to disabilities. During the research, it was clear that this did not override the sense of duty felt by the families to take care of their children with disabilities, but it did lead to shame, frustration, and stress.

2. Isolation and communication challenges

According to the interviewed family members of women or girls with disabilities, families feared the imposed stigma of having children with disabilities. They kept very closed social networks, limited to the family living in the household, especially if the children were female. As a result, the women and girls with disabilities felt compelled to self-isolate as a mechanism to mask the unhappiness and anger caused by direct insults or frustrations.

Women and girls with speech and hearing disabilities felt isolated as a result of the barriers they experienced in communicating with others. Most interviewed women and girls with disabilities said that their family members often ignored them and did not spend time with them. At the same time, the interviewed family members were unaware that this behaviour could be seen as neglectful. They believed that by providing for the girl or woman with a disability, and assisting her with her daily tasks, they were meeting her needs. Family members did not appear to consider the emotional and psychological needs for companionship and friendship that the girl or woman may have.



“I didn’t say anything to anyone about how they [physically] harassed me, not even to my parents. If I told them, it would bring me more trouble and people would start saying bad things about me. So instead of that, I told my father to change my school.”

- Young woman with cognitive and speech disability from Kurigram, Bangladesh



“We have a school right next to us, but because of her disability, the school children would talk about her, taunt her. She used to cry about it. That’s why she didn’t go to school later. The children used to talk harshly to her. She couldn’t stand it. If environment there wasn’t so bad, she could have gone to school there.”

- Father to young woman with mobility difficulties from Kurigram, Bangladesh

3. Future perspectives

Of the 24 interviewed women and girls with disabilities, only eight were attending school. The majority had either dropped out of school (#=8) or never attended (#=8). The opportunity for learning and broadening of social networks provided by school was appreciated and made a difference in the sense of pride and autonomy of many of the participants. However, it was also reported to be a source of frustration, mostly because school attendance did not always lead to opportunities for employment. This is confirmed by the fact that very few research participants had an income generating activity (#=4), with only one being an entrepreneur. All these participants were living in an urban setting.

Families living in urban areas have been able to better provide support to women and girls with disabilities for their education, and participants belonging to these families had more confidence in their own abilities. Moreover, three research participants living in rural areas referenced the support and encouragement received by their siblings who were studying or working in urban settings.



“My other daughter passed high school; she is married now. I could not spend much for this one. What is the point? She would not be able to work anyway.”

- Father of a young women with mobility disability from Kurigram, Bangladesh



“My elder sister who lives in Dhaka, gives me everything: clothes, money, food, many things. My brother gives me dresses, hair oil, and soap...they will always help me.”

- Girl with cognitive disability from Kurigram, Bangladesh

Most participants said that they did not have friends or acquaintances with disabilities in their neighbourhood. Out of 24 respondents, only two were involved with a NGO that works with persons with disability. The other 22 were not members of any OPD and said that in their area, there were no OPDs working with persons with disability.



“Whenever they receive an invitation, all of them go but they do not take me with them. They ask me to stay at home and look after the goats and hens. No one wants to invite a girl who looks ugly.”

- Young woman with mobility disability from Kurigram, Bangladesh

The interviewed OPD members admitted that with their limited organisational strength, they were yet to start activities for women with disabilities in remote rural areas who were unable to reach out themselves. Because OPDs mostly work with the Department of Social Welfare, related government agencies, or NGOs, they often concentrate their efforts in sub-district headquarters and are therefore unable to work in remote rural areas.

Most participants who lived in urban settings referred to television as an important and preferred channel of information and companionship. In rural settings, there was no access to communication media, other than neighbours.

4. Sexuality and access to related information and services



“I am not married so I don’t see how things like sexual health should matter to me.”

- Woman with mobility and visual disabilities from Kurigram, Bangladesh

Social conservatism and the strong influence of Islam and Hinduism has kept pre-marital sex a taboo in Bangladesh, especially in rural areas. Despite the fact that there is no specific law condemning pre-marital sex, it is considered a crime by most people. Arranged marriage is the norm, and girls are not allowed to mingle with boys, or date them. While pre-marital sexual relations still happen, they are considered to be indecent and shameful by most people. Pregnancy of an unmarried woman often leads to a community meeting where the pregnant woman and her parents are publicly humiliated. As women with disabilities are often and erroneously believed to be asexual, pre-marital sexual relations and pregnancies among them are often left undiscussed, bringing even more shock and shame when they happen and become public.



“She doesn’t understand these things: marriage, relationships. I have never talked to her about these things.”

- Mother to young woman with physical and cognitive disability from Kurigram, Bangladesh

According to the interviewed women, in Bangladesh married women accept that their sex-life is largely controlled by their husbands, with limited say in the matter of when or how to have sex or birth control. Women and girls with disabilities shared their believe that it is a woman’s duty to control her own urges, and to engage in sexual relations and reproduction only after marriage and as her husband desires.

Only two married women and girls with disabilities in this research were using short-term contraceptive methods. One used to receive contraceptive injections, but discontinued them after her divorce. The women who were currently using contraceptives said they were influenced by their husbands to do so. In one case, a husband suggested a long-acting contraceptive method following his wife’s accident that led to a mobility disability. In the other cases, women were informed and sensitised by health workers who either visited them at home or lived in the neighbourhood.

Four of the women and girls with disabilities had used ANC and PNC services during the birth of their children. It is important to note that none of the girls with disabilities under 18 years old said that they were familiar with SRHR or had used such services. They were also unlikely to have received any form of information about sexual and reproductive health, with the exception of menstrual hygiene.

The outcomes of marital relationships were expected to be extremely poor. Most married women with a disability in this research expressed constant fear that their husband would leave them for someone ‘normal’. They perceived that they were not equal partners to their husbands. In fact, two women and one healthcare provider said that family members, relatives, and neighbours try to persuade the husbands of women with disabilities to remarry.

Abuse by spouses or their families (i.e., the in-law family to women with disabilities) was reported by families, and the women themselves, as a “lesser” problem when compared to the consequences of divorce and abandonment. Many participants maintained an abusive and deteriorated relationship in the name of the social capital it provided. Of the women and girls with disabilities interviewed, seven (around 30%) shared experiences of abuse: four women interviewed experienced domestic abuse or abuse from an elder brother, and three experienced abuse from community members (incl. neighbours or school mates). None of these seven women and girls have reported abuse formally. The actual number of women and girls in this research who experienced SGBV is assumed to be much higher, considering what is known about the reluctance of the majority of GBV survivors to disclose abuse due to feelings of shame and fear of reprisal.



“My father has not been able to pay my dowry, so they started torturing me. My mother-in-law asks me to bring money, she calls me names and even beats me.”

- Young woman with physical disability from Kurigram, Bangladesh



“There are incidents where an intellectually disabled person was sexually abused every day and she didn’t even understand what was happening. She got pregnant but she was not aware of this.”

- Health worker from Kurigram, Bangladesh

Interviewed women and girls with disabilities reported having a very limited say regarding when and why to seek medical help. They were very reluctant to contradict their families, whose support was acknowledged as a duty and a sacrifice. This unspoken empathy perpetuates the idea of everlasting gratitude and obedience, contributing to dependent relationships.



“She doesn’t understand anything. We have never discussed the nature of physical relationship between man and woman with her. No one from the house has alerted her about such things.”

- Sister-in-law of a woman with cognitive disability from Kurigram, Bangladesh

In Bangladesh, women with cognitive disabilities are often considered as ‘children’ by their families. There is a commonly held belief that girls with cognitive disabilities will not go through puberty and do not have any sexual needs. Because of some of these harmful assumptions, many girls are denied access to SRHR information as it is assumed to lead to risks of inciting curiosity that they cannot manage.

Unmarried women or girls with disabilities expressed that they tried not to think about sex, sexual rights, or pregnancy. Only two girls and three women with disabilities mentioned an awareness of their sexual rights, what to do in case of unwanted pregnancy, and where to go for sexual and reproductive health services. All other participants deferred the questions. Possibly influenced by the presence of caretakers, the interviewed women and girls showed a lot of discomfort when asked to address this topic.

The silence around women and girls’ sexuality leads to very poor knowledge about their own bodies,

sex life, and contraception, as well as reducing their awareness of potential symptoms or complications of a gynaecological nature. As a result, in most cases, girls and women with disabilities lack the opportunity to take control of their sexuality, including their reproductive choices.



“Some disabled people have mental problems. So, it would be difficult for me to get my words across. If they are suffering from cognitive disability, then it would have been a bit intimidating to deal with them.”

– Female family health worker from Kurigram, Bangladesh

Health workers in this research expressed a lack of knowledge and discomfort in how to communicate with girls and women with cognitive and auditory disabilities, relying on family members to convey their messages to the person with disability who was receiving the service. They were often unsure if the family members were able to accurately communicate the needs of the woman or girl, and subsequently, the suggested treatments.



“I went to talk to the doctor. He was not willing to talk to me. He said: Why are you talking to me? Let me attend my normal patients first, then I will talk to you.”

– Young woman with physical disability from Kurigram, Bangladesh



Dhaka at rush hour

Discussion

This study explores the lives, habits, and ambitions of women and girls with disabilities, and the attitudes of members of their communities, in Uganda and Bangladesh. The findings are presented here as described by themselves and their families, health providers, and others. The analysis of the interviews carried out reveal a number of different factors that influence women and girls' perception of their own agency, and the ability to exercise their rights and access SRHR information and services.

Social norms are unspoken rules among a given social network. Through identifying such rules, it is possible to understand what makes people feel safe, respected, and valued when adhering to a certain practice, e.g., enjoying a sexual life and accessing SRHR services. The expectations of others have a strong influence on whether an individual "feels right" when being curious about certain information, expressing sexual desire, or when accessing a service.

Societies have mechanisms in place to socially evaluate individuals' actions. It is important to look at how women and girls with disabilities perceive these social norms, the way they comply or do not comply with them, and how this impacts their access to SRHR information and services.

This research confirms the findings of previous studies focusing on disability-based barriers women and girls with disabilities face to fulfil their rights of choice, sexuality, and access to services (WHO, 2009) (K.G. Santhya, 2015) (Mariani, 2017) (Rohwerder, 2018). This research also looks at the intersection of disability, gender, and age as key influencing factors in the lives of the participants and their relation to social and cultural norms.

The following section will interrogate the key findings from the research through the lens of barriers and enablers for access to SRHR information and services, using the four main research questions as a framework.

1. Key gatekeepers of access SRHR information and services



"Women get this kind of information mostly from their mother, grandmother, sister, sister-in-law and other family members."

- Female family health worker from Chattogram Bangladesh



"It is our father who we approach when we need sanitary pads."

- Sister of a girl with auditory disability from Yumbe, Uganda



"I learned about these (sexual and reproductive health) from my sisters, but they had some misconceptions. Later when I volunteered with an NGO, I realised that I had some wrong ideas about menstruation and pregnancy."

- 22-year-old woman with mobility disabilities form Chattogram, Bangladesh



“My mother puts me on the wheelchair and takes me to the health facility when I am unwell. The period? Sex? Family Planning? I don’t know what that is. “

- 15-year-old girls with hearing and mobility disabilities. Yumbe, Uganda



“I’ve never used Family Planning. My husband doesn’t allow me to use it. He says it is against God.”

– Young woman with auditory disability from Yumbe, Uganda



“My grandmother is the one who showed me what to wear when I started my period.”

- Girl with hearing disability from Yumbe, Uganda

The degree of awareness about basic rights, general information, decisions, and access to information about SRHR, and the ability to exercise those rights, is guarded and defined by key gatekeepers (Burke, Kebe, Flink, van Reeuwijk, & le May, 2017).

In both Uganda and Bangladesh, the main social network of women and girls with disabilities was composed of the household level family members. Although this is also the case for women and girls without disabilities (Burke, Kebe, Flink, van Reeuwijk, & le May, 2017), because of the social isolation that many women and girls with disabilities experience, the action of gatekeepers is also likely to be more impactful.

The dependency that research participants had on their families seemed to be more accentuated in Bangladesh than Uganda – this may be as a result of the stronger or tighter protection practices embedded in the country’s social and religious norms. It also seemed that girls with disabilities in particular were reluctant to contradict or question their parents or guardians. These contextual factors related to social norms, culture, religious, and gender norms can intersect to increase challenges around access and uptake of SRHR information and services for women and girls with disabilities.



“We did not discuss family planning with her. We will make that decision if needed. She is married for one year. If she gets pregnant now, ok. We will see what to do after they have 1 or 2 children.”

- Mother to young woman with speech and cognitive disability from Kurigram, Bangladesh



“I married at 12 years old. My sister-in-law told me about sex and my mother-in-law taught me what to do and not to do.”

– Woman with mobility disability from Kurigram, Bangladesh

In this research, family members, be it mothers, aunts, grandmothers, sisters or, in the case of married women, spouses and mothers-in-law, played the strongest ‘gatekeeper’ roles, contributing significantly to the lives of the women and girls with disabilities, what they could expect from society, and whether or not they could access SRHR information and services.



“My husband is supportive – he tells others that I am enough as a wife. He doesn’t need another one. My father-in-law told my husband, “You have to make your marriage work with this girl. I brought her to our family as a bride when she is well. You have to stick by her.”

- Woman with physical and mobility disability from Kurigram, Bangladesh

This key ‘gatekeeper’ role played by family members can enable or limit access to SRHR services for women and girls with disabilities, depending on the prevailing social norms, culture, knowledge, experience, and attitudes.

The centrality of influence of family members living within the household of women and girls with disabilities offers an opportunity to leverage a sense of responsibility and protection mechanisms within families, introducing awareness about the effects of discrimination on their children’s wellbeing (Rohwerder, 2018) (Werner, 2016) and of women with disabilities living in the family.



“She is not fully intelligent yet, as she is disabled and her intelligence is a little less than that of a normal child. She can’t say if she has any problems. She does not see or feel that she has a problem. She is still like a little child - she doesn’t understand these things (SRH) yet.”

- Mother to girl with physical and speech impairment from Kurigram, Bangladesh

From the interviews conducted during this research, it emerged that while families are the key gatekeepers to access services, they can often overlook the healthcare needs that girls and women with disabilities may have, including SRH. For example, family members did not refer to or demonstrate awareness of the social and emotional needs of the women and girls with disabilities living in their family, as if these were not a priority.



“Disabled women don’t get to express their opinion and they don’t get to take part in the decision making of the family.”

- Female family health worker from Chattogram, Bangladesh



“Mothers bring their daughters who are mentally impaired for long-acting methods. They say their daughters run away from home and they are worried that they will get pregnant.”

- Health provider at Arua Referral Hospital, Uganda

In Uganda, girls with disabilities who had previously received information about sexuality and reproductive health, did so from their mothers, aunts, or sisters within the household before marriage. However, in Bangladesh, they were more likely to only receive such information upon getting married. This practice is consistent with other socially conservative contexts where conversations about sexuality for younger and unmarried women are taboo. Overall, the research findings reflected other studies that describe discussion on sexuality related matters between parents and young people with disabilities as a very infrequent occurrence (Kassa et al, 2016).



“My friend who is a doctor told me about family planning. He sees me as someone who will not manage having kids and I agree with him.”

- Refugee woman with mobility disability from Arua, Uganda



“The first time I heard about family planning was when I overheard a group of women in my neighbourhood discussing it.”

- Girl with mobility disability from Arua, Uganda

The research showed that health providers also have decision-making power regarding SRHR services when they are visited by girls or women with disabilities and their caretakers. Some interviewees shared events in which peer health providers made off-record recommendations to families based on their personal beliefs, such as hysterectomies or the use of long-acting methods, often without the awareness or consent of the woman or the girl with disability. Supporting literature shows that this compliant negative attitude is possible because it is often undetectable in health system records (Frohman, 2013).

Due to misconceptions of disability, discrimination against persons with disabilities, communication difficulties, and the ignorance surrounding their rights, women and girls with disabilities are often subjected to forced sterilisations and other SRH related coercive practices. It is very important to create awareness among persons with disabilities and their social networks and to build capacity among health workers to address negative attitudes and discrimination, ensuring full un-coerced and informed consent (Fraser, Corby and Meaney-Davis 2021)

The lack of communication about aspects of sexuality and sexual and reproductive health, exacerbated by an overprotective attitude held by key gatekeepers, can further reinforce barriers for women and girls with disabilities to access information and services. This often results in very poor knowledge about their own bodies and sexual lives, contraception, and potential symptoms or complications of a gynaecological nature. In addition, if women and girls with disabilities do access health care facilities, health care workers themselves can also play an important role as gatekeepers to the services and information provided; as a result, women and girls with disabilities face more barriers to take control of their sexual lives and reproductive choices, with limited autonomy when it comes to self-identification of health problems and health seeking behaviour.

2. Socially imposed barriers and enablers to access SRHR information and services



“People say if you are disabled like me, you have to get Family Planning”

- 26-year-old woman with mobility disabilities from Arua, Uganda

As previously noted, families of women and girls with disabilities are bound by different norms which are defined by their communities and societies. This in turn impacts their attitudes towards accessing SRHR information and services. According to Hofstede’s cultural dimensions, both Uganda and Bangladesh are collectivist societies with a low individualism score (Hofstede, 2001) (Hofstede Insights, 2021) (Möllerherm Julia, 2019).

This is important in relation to the influence that normative information has on attitudes and behaviours towards individuals, and in particular, women and girls with disabilities. The consistent prioritisation of group rules over an individual’s needs, goals, or wellbeing, and the dependence and obligations of individuals towards their groups, has a clear reflection on the way women and girls with disabilities are entitled to make decisions or display emotions and needs (Mostert, 2016). This also has an impact on women’s and girls’ attitudes or autonomy when decisions must be made concerning their sexual life and reproductive health.



“My husband is a religious man. He finds some of the services offered at the clinic to be immoral. In fact, he objects to family planning since it goes against the will of God. I tend to agree with him on these things.”

- 42-year-old married woman with visual disability from Sitakundu, Bangladesh

Men need to be consulted on decisions around the number of children a woman can have and whether or not she can use family planning.

In addition to the dependencies and obligations of individuals towards their groups in both countries, gender norms and age are very strong factors that influence women and girls’ autonomy, attitudes, and access to SRHR.



“Things are not the same for men and women. If a woman is disabled, she can’t walk, can’t do anything, can’t have children, and can’t take care of the children. But if a man is disabled, there is no such problem.”

-46-year-old woman with mobility impairments from Kurigram, Bangladesh

Men and boys with disabilities are granted more opportunities to marry, to explore employment and relationships, and participate in decision-making. In Bangladesh, even in families without masculine figures, unemployed men with disabilities are still generally viewed more favourably than their female counterparts. This is due to the perception that these men are the natural continuers of the family name and can still bring a dowry to the family.



“It is difficult to find a suitable boy for my sister because some of our neighbours advise the suitors not to marry her - they say that she will not be able to handle household work well.”

- Brother of a young woman with hearing disabilities from Cahttogram, Bangladesh

In both Uganda and Bangladesh, a woman with a disability (independent of the type of disability), is labelled as “less feminine”, a woman who does not entirely fulfil what it means to be a “woman” (Hanass-Hancock, 2009) (Ando, 2017). The imposed concept of a ‘lesser woman’ harms self-perception and self-efficacy. Women and girls have limited control over their intimate relationships or marriage. Instead, their initiation to sex, and their marriages, are often arranged, with strict restrictions according to the gender and religious norms in each country. Women and girls with disabilities in both countries mentioned how they felt embarrassed about the topic of sex because they thought that in the eyes of society, this was wrong of them.



“Whenever they receive an invitation, all of them go but they do not take me with them. They ask me to stay at home and look after the goats and the hens. Nobody wants to invite a girl who looks ugly.”

- Young woman with mobility disability from Kurigram, Bangladesh

Research participants reported that the general social expectation is that a woman or girl with disabilities, like any other woman, should get married, perform household chores, and respect religious, gender, and relationship-related norms, including motherhood. However, because of her disability, she is not socially expected to be a good intimate partner. Women and girls with disabilities are expected to marry and have children, however, the understanding is that the

marriage is a sacrifice of her spouse or partner and does not have equal value to that of a marriage to a woman without a disability. In Uganda, women reported that when a man is interested in them, regardless of how they are treated, they should be happy. Women with disabilities feel that they are not entitled to ask their partners about sex. They should simply consider themselves lucky.

In Uganda, some women and girls from traditional societies, with or without disabilities, are introduced and exposed to sexual practices with men in the hope that it results in the beginning of a relationship. This situation has consequences on a woman’s perception of sex and her vulnerability to abuse. In Bangladesh, minors and unmarried women and girls are extremely protected in an effort to maintain their virginity. Their exposure to sexuality is delayed until the family is able to arrange and afford a marriage.

The interplay of these religious social and gender norms surrounding intimate relationships may indirectly lead to the sustenance of abusive and discriminatory practices against women and girls, something that those with disabilities are particularly vulnerable to. (Burke, Kebe, Flink, van Reeuwijk, & le May, 2017).

When women and girls with disabilities, with the support from their social safety nets and family members, are able to resist against gender and disability-based discriminatory misconceptions and restrictive social norms, it can have a positive impact on self-perception and on practicing individual sexual rights.

In Bangladesh, the few women with disabilities who had a positive perception of their own sexuality had a supportive network. Researchers identified one woman in Kurigram and two women in Chattogram who consider themselves to be ‘pretty’ and ‘desirable’. Two of these women are married and say that they have regular and happy sex life.

Literature indicates that age may be a very strong vulnerability factor in these contexts, because youths are isolated from access to information and decision-making. The additional vulnerability factor of disability, combined with age and gender, results in barriers to SRHR services that are even more exacerbated for young persons with disabilities. For example, young persons with disabilities have emphasised barriers and challenges to accessing SRHR information and services that are more related to age, than to their disability (WHO, 2010) (K.G. Santhya, 2015) (Burke, Kebe, Flink, van Reeuwijk, & le May, 2017).

In Uganda, the majority of interviewed girls with disabilities did not know about contraceptive methods. The girls who did know about contraceptives believed that they were too young to use them. They also stated their desires to have multiple children once they were married.



“My other daughter has passed HSC; she is married now. I could not spend much for this one. What is the point? She would not be able to work anyway.”

- Father to young woman with mobility impairment from Kurigram, Bangladesh



“I always tell my daughter not to talk to boys. If I am not home then she should not let anyone enter into the house. I don't want any unfortunate situation for her so I try to warn her beforehand.”

- Mother to girl with mobility impairment from Kurigram, Bangladesh

Among the participants from communities in Uganda and Bangladesh who had children with disabilities, some reported viewing their children's disability as a burden (independently of the type of disability), instead of as a resource to be able to support the family. The interviews showed some indications that the perceptions of burden may be based on different life experiences, such as limited economic resources (e.g., transport costs) to overcome the barriers faced by the child, fear of being stigmatised as a family, or ongoing anxieties that the child with disabilities might be abused.

Although this did not represent a key focus of the research, overall, it emerged that perceiving children with disabilities as a burden or a resource seems to depend very much on socioeconomic opportunities, and the restrictions and barriers faced by the child with disabilities and their family. These factors influence the way family members support or overlook the needs and rights of children with disabilities, including those related to SRH.



“People say mean things [about my disability]. Even if they do not say it to my face, they say it to my children. They come home and cry about it.”

- 32-year-old woman with physical disability from Kurigram, Bangladesh

Different types and causes of disability are subjected to different perceptions in society, passed on through public misconceptions and worsened by the lack of a proactive health seeking behaviour (Rohwerder, Disability, 2018) (Al-Ghaib, 2017) (Hughes K, 2012). Misconceptions are often disability-specific and reinforce social isolation and the sense of dependency of women and girls with disabilities. This not only decreases the self-confidence of women and girls with disabilities, but reinforces the conceptions of dependency and isolation (Rohwerder, 2019). In addition, misconceptions and social isolation are increasing the risk of violence and SGBV for persons with disabilities.

The prevalence of different types of misconceptions about disabilities, leading to the discrimination and abuse of persons with disabilities that was observed in this research, confirms something that is well documented in existing literature (Rohwerder, 2018) (Aley, 2016) (Stone-MacDonald, 2014) (Bunning, 2017). Myths associated with disability at birth, often based on witchcraft and condemnation (Uganda) or God's will (Bangladesh), have a very stigmatising role for families.

One common belief observed in both settings is that genetics heavily influence the transmission of disabilities across families. However, these misconceptions about fertility were not shared by women and girls with disabilities who participated in this research. Instead, some expressed frustration about these ideas. Women with disabilities who had children without disabilities reported being equally affected by these misconceptions from the wider community, as well as the household environment (such as in-laws). In Bangladesh specifically, it was reported that these myths also affect siblings and their chances to marry or have children.

The less manageable a society perceives a disability to be, the more controlled the social environment of women and girls with disabilities is (M. Tanabe, 2015). For women and girls with cognitive disabilities, this perception worsens the discrimination they face and

the chances they have of interacting with others. Those interviewed in this research choose to self-isolate and stay at home to protect themselves from public discrimination. This inevitably limits their opportunities to access SRHR information and services.



“I have no friends no one loves me”

- 26-year-old woman with cognitive disability
Arua, Uganda



“I stopped going to school in Sudan in P.1. When I was in school, the children would call me bad and mad, and I would beat them. People would call be troublesome. Now I don't want to go back to school because people will insult me and say I have a sickness which will make me ashamed”

- 18-year-old refugee girl with cognitive disability from Yumbe, Uganda

The research reiterates how important it is that family and communities understand that self-isolation is unhealthy. Without this understanding, they are more likely to follow restrictive social norms by making decisions on behalf of their daughters or spouses with disabilities and not affording them the freedom to decide on their own. Previous research indicates that strategies that counter the “rightfulness” of a norm (e.g., raising awareness of the fact that women and girls, with and without disabilities, can be sexually active and in need of SRHR information and services, which they have a right to access) are not effective in societies where most individuals' attitudes align with that norm. Instead, strategies should focus on changing attitudes and empowering a core group of influential individuals (i.e., direct family members living in urban settings), who can, on their own, represent a counter positive norm and create buy-in of the larger group (Cislaghi, 2018).



“We don't have that much property to marry her off. And there are so many bad things happening in the neighbourhood that it is stressful to consider marrying off a disabled girl. If a boy marries the girl for money and then leaves her, what will happen?”

- Father to young woman with mobility impairment from Kurigram, Bangladesh

Women participating in this research were generally not granted the right to explore or acknowledge their sexuality, their choice of partner, or the number of children they could have. Additionally, besides facing gender discrimination, women and girls with disabilities had an additional disadvantage in societies with active dowry practices. In Bangladesh, it is the women's parents that pay a dowry for the marriage of their daughter, and this value is likely to increase if the daughter has a disability. This institutionalised discrimination further cements the concepts of inequality and inequity in the lives of women and girls with disabilities.

In both countries, for those who could marry, the expected outcomes or the success of a marriage were poor. Marrying women with disabilities with men with disabilities was not seen as an advantage or priority, unless they came from a high-status family in the community. Instead, participants reported that it is preferred to marry as soon as possible, given the fear of losing opportunities. This means that women and girls with disabilities possibly risk marrying in a context of vulnerability, perhaps as a second wife, or with someone who is much older than them.



“After we got married, his family did not accept it. They thought my disability was a disgrace to their family. They kept telling him to leave me and our daughter. Finally, he gave in to their pressure and left us a few months back.”

- 21-year-old woman with mobility impairment from Kurigram, Bangladesh



“Health workers come and only talk to married women about pregnancy and children. I am not married, so they don’t talk to me. I am unmarried, what would they tell me?”

- Young woman with cognitive and physical disabilities from Kurigram, Bangladesh

According to the interviewed women with disabilities and direct family members, many of them expect that married women with disability will be divorced or abandoned in the long run. This is considered a delayable but inevitable outcome related to their disability. In many relationships, abuse was normalised and accepted as a compromise to retain a relationship. If and when a woman or girl with disabilities is separated from their spouse and partners in-law, they are most likely to return to their own family members, with an increased sense of guilt for their circumstances.

Despite reported poor sexual experiences and discouragement by their families, participants in this research reported a strong desire to have children, as they are seen as assets of support for the future. Furthermore, women with children have increased decision-making power within the family unit and are also more likely to have access to health services as a mother. This remains true for women with disabilities.

The reported desire to have children by women and girls with disabilities is a positive attitude that may be leveraged as an opportunity to promote SRHR beyond maternal health services. This could include positioning SRHR as a service that supports the preparation of a healthy pregnancy or complements antenatal care, with accessible information about SRHR. This may have an empowering effect amongst those attending antenatal care. Additionally, promoting the social benefits of positive maternal and child health outcomes may be a strategic entry point for a more generalised acceptance of service uptake by women and girls with disabilities.



“Most of the health workers don’t know anything, any sign. When we go there, they say why have you come with this child?”

- Grandmother of young girl with auditory disability from Yumbe, Uganda

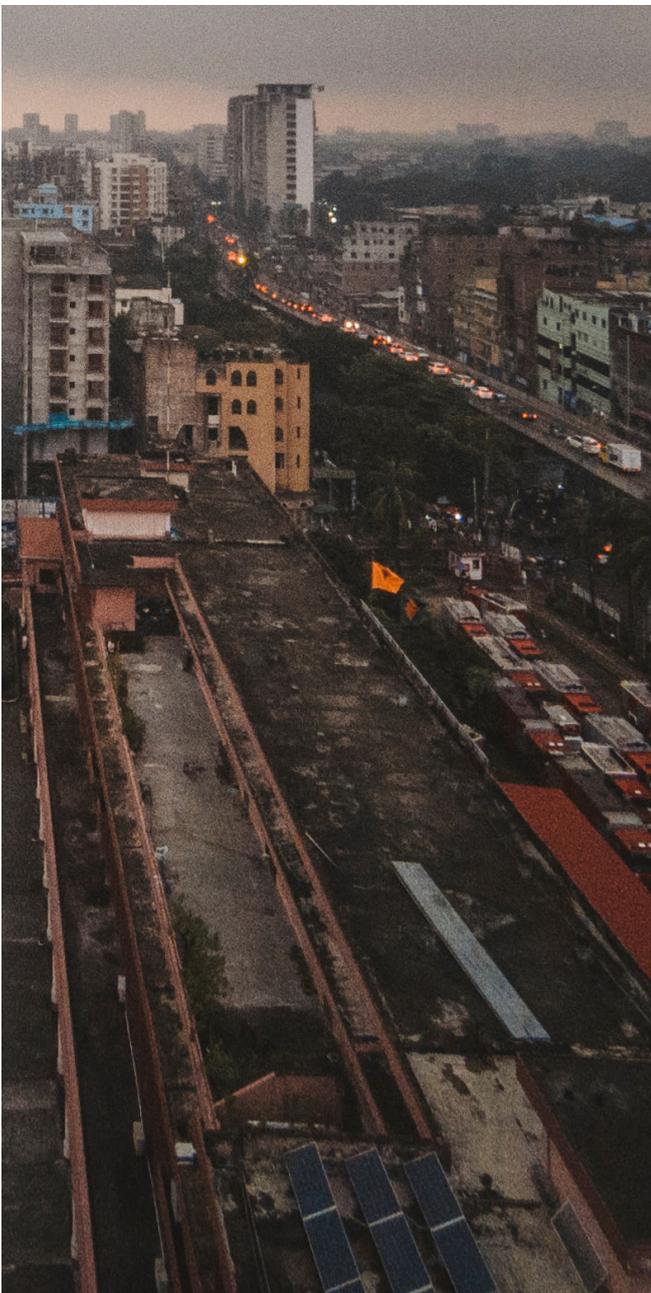


“Not easy for women with disabilities to go to the facility. They say <if I go there how will it look?> The nurses will say <Even this one can come for these services.>”

- Female OPD member. Arua, Uganda

In addition to societal norms that are conservatively opposed to seeking and accessing SRHR services, there is a combination of additional barriers that prevent persons with disabilities from accessing SRHR services. Free access to services can only be effective by addressing all barriers, including a lack of availability, affordability, accessible information, and accessible and non-discriminatory services (Bersamin M, 2016). The lack of mobility autonomy and reliance on aides and family members due to a disability makes the commute to health facilities an additional deterrent against accessing services and support. In both countries, the physical distance to healthcare facilities is a deterrent to women and girls with disabilities accessing the services

they need, often because they need to be accompanied by a family member. Such inconvenient commutes may implicate confidentiality issues for women and girls and may represent a loss of family income. Additionally, health facilities in both countries are described as inadequate and therefore unable to meet the needs of users with disabilities, mostly due to experienced discrimination and frustration when using general services. These negative encounters at health facilities have further reduced their perceived value. In Uganda, despite the availability and presence of outreach clinics carried out within the community, these services were mostly considered inadequate for the interviewed women and girls with disabilities because they happen in public and at a distance from where they live. Further work needs to be done before these services can be considered inclusive.



Dhaka

3. Impact of identified barriers on individual perceptions and sexual and reproductive lives of women and girls with disabilities



“My husband is very fair and handsome. But I am not good-looking. I am boring.”

- Women with physical and mobility disabilities from Kurigram, Bangladesh

Lack of self-esteem is a recurrent characteristic that this study has identified among most of the interviewed women and girls with disabilities. This issue often translated into them doubting their “worth as a woman” and having limited expectations from life, including their marital life. Although the majority of girls and women interviewed acknowledged their right to marry and have children, many felt the need to prove themselves in what the community consider the traditional female roles of wife and mother. Many of the women and girls referred to abuse, violence, and disrespect as something they need to tolerate to maintain their marriage, or something they need to conform to as part of their marital life. In these circumstances, developing the level of empowerment and independence needed to autonomously seek for and access SRHR information and services can be particularly challenging.

More than unable or unwilling, women and girls with disabilities were reticent to express their wishes or feelings. They often seemed unable to oppose the decisions made on their behalf by the family members, particularly in relation to SRHR, or other components of life such as education and marriage.

The isolation that women and girls with disabilities in both settings face, alongside the expectations of not disrupting the wellbeing of the family and the perception of being a burden, often leads women and girls to accept the paternalistic attitudes of others. Most of the interviewed women expressed no interest in accessing psychological support and information about how to cope with discrimination and abuse, as they were unaware that these behaviours existed. For the women and girls with disabilities involved in this research, the

greatest internal barrier to health seeking behaviour was not the shame of being perceived as weaker and vulnerable – or the need to prove their strength to those close to them – but their generalised low expectations about what society could do for them, and the low expectations they had for themselves and the role they could play in the society.



“I didn’t say anything to anyone about how they [physically] harassed me, not even to my parents. If I told them, it would bring me more trouble and people would start saying bad things about me. So instead of that, I told my father to change my school.”

- 23-year-old woman with cognitive and communication difficulties from Kurigram Bangladesh



“One boy raped me 7 years ago. I screamed and some women at the market came to help me. But this was not the first time, I’ve been abused by family members from my mothers and father’s side. My uncle drinks a lot and whenever her get upset he beats me up.”

- 16 year of girl with an intellectual disability from Arua, Uganda



“I feel unsafe when I go outside or travel. I feel like I’m not a normal person I can’t just run away from the situation so how can I protect myself if someone attacks me?”

– Young woman with a physical disability from Chattogram, Bangladesh

Studies have found that women with disabilities are at least twice as likely as women without disabilities to be victims of rape, sexual abuse, and intimate partner violence, with the most common perpetrators being their male partners (van der Heijan and Dunkle, 2017).

The high prevalence of SGBV among the women and girls interviewed for this research, around 30%, confirms the international data on sexual violence against persons with disabilities. Considering that disclosing such an experience is often perceived as very shameful and includes the risk of re-experiencing trauma, survivors often avoid talking about the abuse they have suffered. Moreover, the isolation and fear experienced by most of the women and girls with disabilities who were interviewed, as well as the widespread impunity of perpetrators and lack of protection mechanisms from abuse and violence, limit the opportunities to denounce violence and escape from situations of abuse. This also reinforces the idea that tolerating abuse in silence is a normal aspect of the marital and family experience when you are a woman or a girl with disability. The number of testimonies in these interviews indicates a very high occurrence of SGBV, and most likely, an underrepresentation of the issue.

4. Enabling practices and beliefs that contribute to women and girls' access to SRHR information and services



“Since I am studying, I can look for a good job. That way, I can continue studying alongside working. This would lessen the burden on my family.”

Young girl with physical disability from Kurigram, Bangladesh

Education economic and social opportunities

Women and girls with disabilities who have the opportunity to engage in income generating activities, education, and social interactions within the community at large, and in peer groups, have a higher chance of exercising agency - a fundamental condition to enable women and girls with disabilities to increase their self-esteem and self-identify their own needs (Gurmit Kaur, 2015).



“Before I went to school, I had no friends. Then when I went to school, I made my first friend. Now I have a few friends, and even a best friend.”

- Young girl with physical disability from Chattogram, Bangladesh

Access to school has great potential to help girls and women with disabilities to improve their social status and learn how to take ownership of their lives, including their SRH lives. School was considered in both settings to be an enabling factor for women and girls with disabilities, given the structured intellectual growth and prospects of future remunerated work. However, the following limitations were identified:

1) effectiveness on increasing agency is limited because school settings and the workplace are often environments where discrimination is experienced and reinforced 2) access to education and employment opportunities is strongly influenced by the attitude and behaviours of family members who may encourage women and girls with disabilities to take advantage of these opportunities, but also discourage them or create obstacles to prevent access.

The introduction of different information related to SRHR (i.e., menstrual cycle and hygiene, abstinence) is carried out through schools in both countries (more openly in Uganda than in Bangladesh), but research participants also reported that this information was often un-contextualised, un-actionable and not adapted to the communication requirements of persons with disabilities. In Bangladesh, women are generally restricted from accessing SRHR information before marriage.

By not providing pathways for women and girls with disabilities to access SRHR information, it sends a message that the information is not for them, or that it is not relevant for their lives. This contributes to reducing their access to SRHR information and services.

The presence and concentration of NGOs in the north of Uganda, particularly in refugee settings, seems to be an enabling factor in facilitating equitable access to information. Such environmental factors possibly offer increased opportunities for refugee populations.



“My only wish is to earn. I don't want to be completely dependent on others. I don't want to beg. I pray to Allah that He gives me the strength to take care of myself once my parents are gone.”

- Woman with cognitive and physical disabilities from Kurigram, Bangladesh

Full access to SRHR services for girls/women with disabilities often requires financial freedom. Two-third of the girls and women with disabilities (especially those with no access to education) interviewed in Bangladesh are unable to earn any money, and without support from others, they are not able to pay for transport, medicine, and other costs related to accessing healthcare. They need opportunities to earn, and the freedom to spend their own money. Being able to generate income is a

crucial factor that enables women to have more social contacts, as well as access to information, opportunities to exchange with peers, become less dependent, reduce their feeling of being a burden, strengthen their self-esteem, and improve their perception of having the right to decide for themselves.



“I am someone who is free, I can talk to anyone. I can help people translate to Lugbara, Arabic and English.”

- Refugee woman with mobility disability from Arua, Uganda

In Uganda, older women with disabilities benefit from savings groups organised by persons with disabilities, and from disability-specific associations – mostly focused on hearing and visual disabilities. Younger girls with disabilities who were in school were less likely to be part of these groups as they were held during school hours. These groups were regarded as a great resource for both women and men with disabilities, often leading to healthy romantic relations amongst the members.

On the contrary, in Bangladesh there was almost no mention of such organisations by the research participants. Organisations for persons with disabilities are mostly operating in urban/peri-urban areas and often exist as part of government departments, rather than as independent OPDs. Government organisations mostly reserve allowances for women and girls with disabilities who are registered and listed with the Department of Social Services. The research participants referred to this process as dysfunctional and not transparent. A number of NGOs also offer opportunities for microcredits, but women and girls with disabilities are usually not selected.



“Women and girls with disabilities do not know these things (SRHR). I have a responsibility to share with them“

- (Female leader at ARUA Blind Women Association)

In general, women in both countries have the right and social acceptance to participate in small peer groups where personal issues are shared and discussed. However, the low prevalence, geographic dispersion, and social isolation of women and girls with disabilities are barriers that hinder access and visibility of these peer groups. In addition, a research participant from Bangladesh mentioned that it is common for groups of persons with disabilities to be mocked and verbally attacked. This resulted in shame and deep discouragement for further engagement.

Exposure in urban versus rural settings

Persons with disabilities in urban settings tend to have better access to school, employment, health services, and facilities and technology (UN, 2019). Most of the research participants' families owned a mobile phone. However, less than half of the women or girls with disabilities had a personal mobile phone. Access to communication technology, i.e., television or mobile phones (in Uganda, newspapers and radio were mentioned too) was only reported in urban settings. Those who own or have access to these devices during the day refer to them as an enabling mechanism to feel less lonely, but also more empowered. Across both countries, participants living in rural settings mentioned the importance of having siblings living in urban settings who would occasionally visit, share interesting information, and who are supportive and encourage them to be positive.

The few research participants who had moved from a rural area to an urban setting were mostly confident and educated participants. The decision to move was enabling because it loosened their social ties and increased their sense of autonomy due to improved access to business opportunities. The main drivers in seeking this autonomy include providing financially support to their families in Bangladesh, and gaining the power to purchase items of their own choice in Uganda.

Conclusion

This research contributes to a deepening of the existing understanding about enablers and barriers of access to SRHR information and services for women and girls with disabilities, in low and middle-income countries.

Women and girls with disabilities in these contexts have very few chances to exercise their agency because they are economically dependent, socially isolated, and have difficulty finding peers to relate to, especially in rural areas. They can be viewed by others and see themselves as not completely fulfilling the definition of womanhood, living lives where family members play a decisive role in self-determination and exposure to life outside the family sphere. Conservative norms related to gender, age, and disability intersect to increase barriers. These factors are major determinants to hinder access to SRHR information services.

Gender-based violence is extremely prevalent and can contribute to over-protection and social isolation practices by families. The stigma and shame related to GBV discourages women and girls with disabilities to access help, and fear of abandonment contributes to the view that GBV is almost inevitable and must be tolerated.

The low expectations that women and girls with disabilities have of themselves, and their disconnected experience with health services, limits their ability and motivation to seek support. In this research, it is proposed that access challenges may potentially be addressed and removed by working collaboratively with women and girls with disabilities and the family members living in their households, and through school and peer group support.

Amplifying social context through education opportunities and involvement in OPDs and peer groups has a positive influence; education and economic opportunities are key in reducing the sense of isolation and increasing self-esteem, resilience, and agency. Additionally, there are opportunities to improve the health system's response to the needs of women and girls with disabilities through more intentional efforts at delivery model and infrastructure levels. For example, antenatal, birth, and postnatal care are key entry points for women and girls with disabilities to access comprehensive SRH information and services.

Notes for future research

Motherhood and disability

This research described the aspirations of motherhood from women and girls with disabilities. It did not, however, explore in depth the possible impact motherhood may have on the reported self-esteem of and discrimination against women and girls with disabilities. Additionally, further research should investigate how the context of isolation and discrimination against mothers with disabilities affects the nature of mother-child relationships, and what forms of support are required by women with disabilities to ensure their wellbeing (Prilleltensky, 2004) (M. Tanabe, 2015).

Disability and gender norms

This research did not investigate the impact of disability on the masculinity of boys and men living with disabilities. It has nonetheless shed some light on the perception of how the disability of women and girls amplifies and reinforces restrictive gender norms and negatively impacts social expectations. Further research should be conducted to understand the extent to which the same occurs with boys and men, and how this affects their conception of self-esteem and agency (Staples, 2011) (Ganle, 2020).

The power of mutual exposure

We have found some evidence to show the positive impact of OPD membership and the role that women can play as leaders in their community through sharing information. Family members are described as key sources of information for young girls, but there is more to learn about the potential role of peers as education sources. Further research should investigate the impact inclusive peer groups and organised social interaction opportunities have on issues like stigma and isolation.

Not enough has been said on the subject of gender age and disability intersectionality. Further research would help our understanding of this issue and how to better support families and their members with disabilities in meeting their SRH needs and fulfilling their rights.

Recommendations

Following this research, we recommend the following programmatic interventions for the successful delivery of SRH information and services to women and girls with disabilities:

Key gatekeepers

- Support parents and caretakers, such as grandparents, in their role as key gatekeepers, to understand and respect the sexuality of girls with disabilities and to offer them guidance on the options they have to ensure children's self-reliance.
- Emphasise the relevance of sexual and reproductive health and rights to key gatekeepers so they recognise the freedom of women and girls with disabilities regarding SRHR. Gatekeepers should be aware of supporting their family members during the preparation for marriage and sexual relations, addressing their concerns about sexual and reproductive health, ability, and performance.
- Create and support existing peer models among families of women and girls with disabilities that stimulate engagement between similar age groups, geographic regions, and type of disability.
- Address the high risk of SGBV for women and girls with disabilities, with key gatekeepers and SRHR actors (e.g. providing awareness sessions and including training modules on GBV and disability in training curricula for health workers). This cycle of violence is further perpetuated by insufficient attention and action on the issue of GBV for women and girls with disabilities.

Reduce socially imposed barriers

- In co-cooperation with OPDs and SRHR stakeholders, develop strategies that focus on addressing restrictive social norms and misconceptions of disability through Social Behaviour Change and communication strategies.
- To reduce dependencies and increase access to SRHR information, facilitate access to economic and income generating opportunities and education for women and girls with disabilities in both urban and rural settings, as a key factor to increase communication opportunities and participation in social networks.

Positive impact on perception

- Recruit women with disabilities as community health workers with training in SRHR and provide

reasonable adjustments to allow them to do their job, e.g., lowering desks for wheelchair users. Portray their participation as experts in domains that are socially relevant. This may not only increase their social capital and self-esteem, but also the adequacy of services and proactive advocacy among families of women and girls with disabilities.

- Encourage the integration of women with disabilities into existing women's peer groups and address issues related to SRHR that incentivise and inspire their support to other women with disabilities. This experience may promote the exposure between those with and without disabilities, thereby creating reciprocity and empathy.
- Design SRHR information together with women and girls with disabilities to better reflect the lived experience of women and girls with disabilities.

Enabling practices

- Design health programmes to work together with women and girls with disabilities and their family members, targeting young and old men (i.e., fathers, brothers and husbands), and female caregivers of all ages. These family members have a great sense of responsibility that, if matched with a strong understanding of SRHR and the right to informed consent of women and girls with disabilities, can be leveraged to complement the role of health actors – thus, empowering families and communities with distinctive roles in health and wellbeing of their children and siblings and promoting their self-esteem, agency, and independence.
- Design inclusive outreach strategies and referral mechanisms that are empathetic and sensitised to the access challenges of women and girls with disabilities. It would be important to explore the impact of targeted outreach strategies such as door-to-door visits, as well as the advantage of working with peers with disabilities in those outreach activities (M. Tanabe, 2015) by closely cooperating with OPDs and other disability-focused and civil society organisations.
- Encourage open forums for the discussion and dissemination of good practices among health care workers, where women and girls with disabilities or OPDs can participate and contribute. This gives visibility among peers and reduces misconceptions of health care workers. By offering solutions that enhance the social capital of health providers and reward efforts for inclusivity, they are more likely to proactively seek improvements in their services.

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