The untold story of women of reproductive age with intellectual disability in Bangladesh: An insight into sexual reproductive health needs

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Fouzia Hoque

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Master of Public Health
KIT (Royal Tropical Institute)
Vrije Universiteit Amsterdam (VU)
The Netherlands

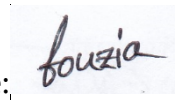
Signature: 

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Table of Content

List of figures and tables

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I would like to dedicate this thesis to my deceased father.

List of Abbreviation

AAP	American Academy of Pediatrics
AIDS	Acquired immunodeficiency syndrome
BWHC	Bangladesh Women's Health Coalition
CRPD	Convention on the Rights of Persons with Disabilities
CSE	Comprehensive sexuality education
DSM-5	The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
DHO	The District Health Office
FMU	Forced Marriage Unit
HCP	Health Care Professionals
HIV	Human Immunodeficiency Virus
IED	Institute of Educational Development
ID	Intellectually Disability
ICF	The International Classification of Functioning, Disability and Health
IQ	Intelligence Quotient
KIT	Koninklijk Instituut voor de Tropen
LMIC	Low- and Middle- Income Countries
MOH	Ministry of Health
NGOs	Non-governmental organizations
RTIs	Respiratory tract infections
SRHR	Sexual and reproductive health and Rights
SRH	Sexual and reproductive health
STDs	Sexually transmitted infections
UCEP	Underprivileged Children's Educational Programs
UNESCO	The United Nations Educational, Scientific and Cultural Organization
UN	The United Nations
VU	The Vrije Universiteit Amsterdam
WHO	World Health Organization

Definition of used terms

A. Women of reproductive age:

Women of reproductive age refer to all women aged 15–49 years (Bantie. 2020)

B. Intellectual disability:

Intellectual disability refers to significant deficits in functional and adaptive skills including the ability to carry out age-appropriate daily life activities and they have an IQ score of below 70 (Normal IQ range in the general population between 85 and 115) (Shogren, 2010). According to severity, ID is four types including mild, moderate, severe and profound (Patel, 2018).

C. Sexual and reproductive health:

Sexual and reproductive health (SRH) are essential for sustainable development because of their links to gender equality and women's wellbeing, their impact on maternal, newborn, child, and adolescent health, and their roles in shaping future economic development and environmental sustainability (Starrs, 2018).

D. Sexual reproductive health services:

All people must have safe access to reproductive health services without having to travel long distances or waste time in order to obtain information, diagnosis, counseling, treatment, and care. SRH services and treatments have to be accessible to all people based on the principle of equity. Reproductive health care is defined as the constellation of methods, techniques, and services that contribute to reproductive health and well-being by preventing and solving sexual health problems (Fathalla, 2008).

Abstract

Bangladesh is an overpopulated, middle income country where disability is a major social and economic phenomenon. Sexual and reproductive health services are yet to achieve in Bangladesh and people still attach to stigma, environmental barriers, social and cultural factors related to SRHR. In Bangladesh, society neglects the equal rights of women of reproductive age with intellectual disabilities in case of SRH needs as those without disabilities though they have the same rights to get access to sexual reproductive health services as others. It is mandatory for women of reproductive age with intellectual disabilities to get accurate, accessible, and understandable information about sexual reproductive health and services regarding contraception and reproduction in lower middle income countries like Bangladesh. The aim of the study is to understand and synthesize sexual and reproductive health needs for women of reproductive age with mild to moderate intellectual disability (ID) in Bangladesh, in order to create awareness in the community, and health care professionals as well as inform public policies and programs supporting women with ID and their families in Bangladesh. A literature review of the published literature in the last 20 years was carried out to meet the study objectives. An adjusted conceptual framework of sexual reproductive health by Kalpakjian, 2020 was used to guide the analysis. The adjusted framework will provide information regarding 5 components including reproductive health issues, knowledge about reproductive health, communication about reproductive health, reproductive health environment, and self-advocacy and identity. There is a lack of significant data found in Bangladesh. But other neighboring countries indicated that women of reproductive age with intellectual disabilities have many issues and needs regarding SRH including pregnancy, contraception's, periods, and sexual behaviors. In addition to this, health care providers do not have enough knowledge and understanding about the extent of disabilities and SRH for women with ID due to lack of training, no guidelines, and inadequate access to resources. Besides, environmental barriers, lack of awareness among women with ID, and self-stigma are also putting obstacles to get access to SRH services for women with ID. This study will be a great initiative to talk about sexual reproductive health needs and services for women of reproductive age with ID in Bangladesh.

Key terms: Intellectual disability, Sexual reproductive health, Bangladesh

Chapter 1: Introduction

1.1 Background

1.1.1 Bangladesh

Asia is the largest continent in the world and contains 60% of the world's population (Jeevanandam, 2009). Bangladesh is an overpopulated country in South Asia with 160.8 million people (Nuri, 2022). It is the 7th most overpopulated nation in the world where half of which are women. Bangladesh is classified as a lower-middle-income country. Although it has experienced rapid economic growth, urbanization, and technological advancement in recent years, the general level of health care in Bangladesh is far below U.S. and European standards. The majority of the population lives below the poverty line, lacks education, has inadequate health, and job opportunities, and is at high risk of natural disasters (Kibria, 2020). Governments and NGOs in Bangladesh have planned many development programs to address the current situation and reach every citizen of Bangladesh. In spite of this, people with disabilities are always at a disadvantage when it comes to receiving any assistance from the Government and NGOs because of a lack of understanding, knowledge, and a negative attitude on the part of the general public (Tareque, 2014).

1.1.2 Disability in Bangladesh

Disability is a human rights issue. According to WHO 2013, "*Disability refers to the interaction between individuals with a health condition, and personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social supports"*. According to the ICF and the Convention, disability is a complex interplay between health conditions and the physical, social, and psychological environment of an individual that limits their full and effective participation in society. A person with a disability requires the same range of health services as someone without a disability, including diagnosis, treatment, maintenance, and restoration of health (Officer, 2009).

There is a high rate of discrimination and negative attitudes towards persons with disabilities in Bangladesh, and they are the most vulnerable and disadvantageous section of society (Zelina, 2010). Due to environmental, social, and cultural barriers, disabled individuals are deprived of

their basic needs and all these barriers prevent them from fully and equally participating in social, economic, political, and cultural activities (Nuri, 2022).

Moreover, in developing countries like Bangladesh, people with disabilities are poorer than nondisabled people and they face difficulties to access education, health services, social support, employment (Rahman, 2021). The national poverty line in Bangladesh was reached by 20.5% of the population in 2019 (Asian Development Bank, 2022).There is a complex and interdependent relationship between disability and poverty. According to Sarker 2021, women with disabilities living in rural areas are more disadvantaged and oppressed than those living in towns (Sarker, 2021).

According to the Protection of the Rights of Persons with Disabilities Act 2013, any individual with a permanent physical, emotional, intellectual, developmental, or sensory impairment who is unable to participate actively in society or whose social participation has been disrupted is considered as disabled (Islam, 2021). About 15% of the world's populace lives with certain forms of disability (WHO & World Bank. 2011), and 80% of them live in lower middle income countries (Saran, 2020). The Bangladesh Bureau of Statistics (BBS) estimated the prevalence of disability in Bangladesh at 9.07% for males and 10% for females (Talukdar, 2018). According to the survey, about 55% of Bangladeshis accept disabled people well, 63% do not believe disabled people are a burden to their families, and about 20% suggested providing extra privileges to these people, such as extra security on roads, reserved seats in public transportation like buses, trains, and separate hospitals and schools (Titumir, 2005). Across the globe, women are more likely than men to suffer from disabilities (WHO & World Bank 2011). Disability is a major public health issue in Bangladesh and they have limited access to medical services (Kibria, 2020).

1.1.3 Intellectual disability

Intellectual Disability refers to a disorder that starts during the developmental period that consists of certain intellectual deficits and challenges in handling aspects of daily life like school, work, home, social life, and health, among other things (American Psychiatric Association, 2013). Intelligence defines the ability that involves reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning efficiently, and learning from

experience (AAIDD, 2010). Historically, intellectual disability has been defined by significant deficits in intelligence, in particular, with an IQ score of below 70, and also by significant deficits in functional and adaptive skills (Shogren, 2010).

Intellectual disabilities are defined by The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition -DSM-5 as neurodevelopmental disorders accompanied by intellectual difficulties and difficulty in conceptual, social, and practical areas of life. The DSM-5 diagnosis of ID requires the satisfaction of three criteria: Deficits in intellectual functioning including reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and learning from experience: Deficits in adaptive functioning that significantly hamper conforming to developmental and sociocultural standards for the individual's independence and ability to meet their social responsibility; and the onset of these deficits during childhood (Papazoglou, 2014). There are four types of intellectual disabilities including mild, moderate, severe and profound (Patel, 2018).

1.1.3.1 Mild intellectual disability

People with intellectual difficulties have deficits in understanding and acquisition of complex language and academic skills. They can reach academic skills equivalent to the 4^{th}–5^{th}-grade level. 85% of persons with intellectual disabilities have mild severity and the measured IQ for persons with mild ID is between 50–55 and 70. With appropriate support, they are able to develop basic skills in reading, writing simple letters, and completing a simple job application (Papazoglou, 2014).

People with mild ID continue to show deficits and limitations in executive functioning such as planning, organizing, priority setting, and abstract thinking and limitations in tasks that require short-term recall. Persons with mild ID are at an increased risk of being manipulated by others and they show limited ability to accurately judge or comprehend the norms of social discourse and interactions, and, often, their behaviour in social situations may be considered immature or inappropriate by others (Shogren, 2010).

A person with mild intellectual disability can learn most of the skills needed for daily household, practical, and self-care activities with appropriate support. It is necessary for people with mild intellectual disabilities to have intermittent support with daily living activities such as assistance

in making healthcare and legal decisions, self-care, shopping, preparing food, and managing money (Shogren, 2010).

1.1.3.2 Moderate intellectual disability

About 10% of persons with ID have moderate severity and are likely to be recognized to have an ID by 3–5 years of age. IQ measurements of individuals with moderate ID range from 35 to 49 and 50 to 55. Persons with moderate intellectual disabilities have difficulty learning and acquiring academic skills, as well as acquiring and developing language skills. Persons with moderate ID show significant limitations in reading, writing, mathematics, and other skills requiring understanding basic concepts. An individual with moderate ID finds it difficult to communicate socially, interact with others, and understand behavior norms appropriate for their age and social context. However, they can develop meaningful family and personal relationships with support. To remain gainfully employed and maintain independence, adults with moderate intellectual disabilities need substantial ongoing support because their decision-making and judgment in social matters are limited. Individuals with moderate ID may be able to perform basic daily living and job skills with ongoing support and teaching. They need continued supervision and guidance in daily activities as well as in performing job-related tasks. It is possible for someone with moderate ID to obtain relative independence in a variety of self-care and daily living tasks, such as getting dressed, removing their clothes, and taking their medications (Shogren, 2010).

1.1.3.3 Severe Intellectual Disability:

A severe intellectual disability (IQ 25 to 40) affects between 3% and 4% of the population with intellectual disability, causing significant delays in development. Individuals with this disability may be able to understand speech, but otherwise have limited communication skills (Sattler, 2002). People with severe intellectual disabilities require close supervision and specialized care throughout their lives. It is possible for individuals with severe ID to perform simple tasks or routines in order to facilitate their own self-care. Individuals with severe ID need supervision in social settings and often need family care in order to perform activities of daily living (Szafrański, 2019). Women with severe intellectual impairment are unlikely to marry or have children (Hall, 2005).

1.1.3.4 Profound intellectual disability.

A profound intellectual disability (IQ 25 or less) affects relatively few individuals with mental retardation (1%-2%) and is characterized by a wide range of deficits in cognitive, motor, and communicative functioning. Physical limitations and limited communication abilities are common among them. Medical conditions associated with mild to moderate disabilities are less likely than those associated with severe and profound disabilities. The majority of profoundly intellectually disabled individuals requires lifetime supervision and care (Szafrański, 2019).

1.1.4: Intellectual disability in Bangladesh

One of the most common developmental disabilities is intellectual disability (ID). It is a lifelong condition and people with ID need additional support from family, friends, society, school, and health care providers. This study will focus on women of reproductive age with mild and moderate ID because about 95% of people with intellectual disabilities (85% mild ID and 10% moderate ID) fall into mild to moderate severity (Shogren, 2010).

The prevalence of Intellectual Disability across the world is around 1% (King, 2009). A study indicated that the prevalence of intellectual disability in Asia is 0.06–1.3% (Jeevanandam, 2009). Low-income countries have a higher prevalence of intellectual disabilities than industrialized nations (Mirza, 2009). This prevalence is almost two times more in lower-middle-income countries compared to high-income countries (Maulik, 2011). There is limited literature on intellectual disability in Asia including in Bangladesh (Jeevanandam, 2009). In Bangladesh, one study was conducted profiles for people with intellectual disabilities in the Dhaka and Pabna regions of Bangladesh and it was published on 2022. This study concluded that from June 2018 to November 2019, 200 intellectually disabled patients were admitted to three Psychiatric Hospitals in Bangladesh (Islam, 2022).

Though there aren’t enough data available on intellectual disability in Bangladesh in neighboring country India, reported the prevalence of ID is 10.5/1000 (Lakhan, 2019). It also depends on urban (11/1000) and rural areas (10.08/1000) (Lakhan, 2019). In India, very limited epidemiological studies have been conducted on intellectual disability prevalence. It has been reported that 2 to 2.5 percent of the general population have ID, which is more prevalent among low-income groups and rural residents (Girimaji, 2011). In Thailand, approximately 1 percent of

the population has intellectual disabilities (Maulik, 2011). In Bangladesh, having a person with an intellectual disability in a family brings financial, physical, social, and psychological hardships (Islam, 2022).

1.1.5 Sexual reproductive health

Everyone has the same right to receive sexual reproductive health services. Women with intellectual disabilities (ID) are a group specifically impacted by the lack of access to sexual health services (Matin, 2021).

1.1.5.1. Reproductive health:

Reproductive Health is defined as "*Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant"* (UN, 1994: 30, paragraph 7.2)

1.1.5.2. Sexual health:

According to the World Health Organization WHO, sexual health is "*the state of physical, emotional, mental and social well-being in relation to sexuality, and requires a positive and respectful approach to sexuality and sexual relationship."* According to Glasier et al 2006, "*Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.*" (Glasier et al., 2006)

Women with intellectual disabilities have many problems with their sexual and reproductive health due to their poor cognition and communication difficulties caused by disability (Ebadi, 2022). A number of barriers prevent women with ID from receiving care, including a lack of provider training and experience, a reluctance to discuss sexual health, lack of sexual knowledge and limited sex education opportunities, disability-related barriers, a higher prevalence of sexual abuse and assault, often underreported, a lack of dialogue about consensual sexual expression, a lack of treatment for menstrual disorders, and legal and systemic barriers (Greenwood, 2013)

1.1.6: Sexual reproductive health services in Bangladesh

Women of reproductive age with ID are facing many difficulties in LMICs like Bangladesh because their basic needs such as housing, medical care, education, employment, transportation facilities, and other opportunities are not met. Bangladesh is a country where disability is a major social and economic phenomenon. People of Bangladesh are still attaching to social, cultural, and religious stigma to issues related to SRHR. The words ‘sex’ ‘sexual’ and ‘sexuality’ are considered taboo and not to be discussed openly or publicly (Nahar, 2022). Sexual and reproductive health services are yet to achieve in Bangladesh for people with disabilities.

Most of the parents and adults in Bangladesh are unwilling to give young people accurate sexual information because they think that knowledge about sex leads to early sexual activity. But they do not realize that accurate and comprehensive sexuality education will empower young people, reduce unwanted pregnancies, unsafe abortions, sexually transmitted diseases (STDs), and respiratory tract infections (RTIs) and enable the health and well-being of young people.

The national education policy of Bangladesh has no mention of comprehensive sexuality education (CSE) but the country has several policies which state the need for life skill education which are yet to be implemented. Bangladesh’s National Youth Policy (2003) includes a focus on raising awareness about STDs, HIV, and AIDS, enabling young women’s decision-making on reproductive health, empowering young women, and expanding facilities for young women’s education and for reproductive health services for young people. This policy is currently being revised and the revised content is reported to include SRH issues (Amin, 2020).

The Bangladesh government has signed and ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) and passed the Disability Rights and Protection Act in 2013 to ensure

that people with disabilities receive the same level of care as everyone else (Nuri, 2020). Although it has expressed interest in promoting sexual and reproductive health and rights (SRHR) for persons with disabilities, little attention has been paid from the Bangladesh Governmnet to this issue till now. In Bangladesh, SRH services are available for the general population. Currently, some national and international NGOs are undertaking a number of activities and offering youth-friendly services related to youth and adolescence reproductive and sexual health i.e., vouchers scheme, helpline, face-to-face counselling, clinical services, social gathering, social media campaign, etc. The Bangladesh Women's Health Coalition (BWHC) established in 1980, is the first organization in Bangladesh to start working on sexual and reproductive health services and rights for deprived and underprivileged women. The Underprivileged Children's Educational Programs (UCEP) and the Institute of Educational Development (IED) are also working in this sector in Bangladesh. Recently, little attention has been given to sexual reproductive health services for people with physical disabilities. But it is also crucial to start working for women of reproductive age with mild to moderate ID in Bangladesh. The majority of people with intellectual disabilities (95%) are classified as having mild (85%) to moderate (10%) intellectual disabilities (King, 2009) and they get married and have children (Hall, 2005).But women with severe and profound intellectual impairment are unlikely to marry or have children (Hall, 2005). This is why this study will focus on women of reproductive age with mild to moderate intellectual disability in Bangladesh. So, this study will be an initiative to talk about SRH issues, needs and services for women of reproductive age with mild to moderate intellectual disabilities in Bangladesh.

1.2 Problem Statement and Justification

Bangladesh is facing an increasing demand for health services and sexual reproductive health remains an area of concern in the context of meeting the Sustainable Development Goals (SDGs) in health and women's empowerment. Only the formal public health system provides few services for sexual and reproductive health issues. In Bangladesh, the number of maternal deaths is high whereas 14% of mortality is caused by violence during pregnancy, and 26% of mortality is caused by the complications of unsafe abortions attended by unskilled birth attendants. There were 8.76 million Bangladeshi women suffering from chronic morbidity in 2003, due to vesicovaginal and rectovaginal fistula, uterine prolapse, dyspareunia, hemorrhoids, and other

illnesses. There is an unmet need for sexual reproductive health services among women in South Asia (Sabina, 2011).

Sexual and reproductive health is a public health concern and a human rights issue for both men and women but women bear the major share of the burden of sexual and reproductive health issues. Globally, sexual and reproductive health shows glaring inequities between developed and developing regions (Fathalla, 2008). Women with intellectual disabilities face barriers to health care access, including limited opportunities for sex education, inexperienced healthcare providers, disability-related barriers, high prevalence of sexual assault, and abuse, undertreatment of menstrual disorders, hesitancy to talk about sexual health, unwanted pregnancy, and many others (Greenwood, 2013).

In general, all women with intellectual disabilities receive significantly less information than their peers about contraceptive options, sexually transmitted disease screening, and breast and cervical cancer screening (Walters, 2018). In addition, women of reproductive age with ID have a higher risk of unwanted pregnancies and sexually transmitted diseases due to limited access to reproductive and gynecological care (Abells, 2016). It has also been reported that people with intellectual disabilities need more sexual and reproductive health (SRH) care and services than people without disabilities because of their limited cognitive abilities, which is often ignored in most low- and middle-income countries, including Bangladesh (Amin, 2020). But in Bangladesh, women with ID are seen as incapable of reproduction, asexual or hypersexual, and incapable to get married as well as SRHR for women with intellectual disabilities is overlooked though access to this information and services are fundamental rights for them (Amin, 2020).

Moreover, society neglects the equal rights of people with disabilities in the case of SRHR as those without disabilities. Women with ID seeking SRH services also face negative and disrespectful attitudes from service providers (Matin, 2021) whereas they need special attention from healthcare providers to ensure the best quality of care. It is important for them to get accurate, accessible, and understandable information about sexual health and options regarding contraception and reproduction but information about SRH aren’t accessible to them. It is also a matter of concern that women with ID don’t have the opportunity to discuss sexual matters, pregnancy desires, and concerns with healthcare providers because of environmental and

attitudinal barriers. This is why; women with ID do not get appropriate screenings, contraceptive services, preconception, and prenatal care (D'Angelo, 2022).

Moreover, women of reproductive age with ID have the same rights to get married as individuals without disabilities. Due to their incapacity to make decisions, they are victims of forced marriage. In addition, they experience challenges in understanding people's cognitive perceptions and communicating with others (D'Angelo, 2022) which makes it more difficult for them to report depression or abuse (Groce, 2014). According to the Forced Marriage Unit (FMU), the number of people with ID who are subject to forced marriage is increasing day by day and the majority of forced marriages to women with ID occurred in Bangladesh (9.8%), Pakistan (42.7%), India (10.9%), Afghanistan (2.8%), Somalia (2.5%) and Iraq (1.5%) (Groce, 2014).

Globally, poor pregnancy outcomes are more likely among women with intellectual disabilities like as gestational diabetics, a high rate of pre-eclampsia, poor breastfeeding, and so on (Rubenstein, 2020). The chance of being pregnant is the same among women with ID and women without disabilities. But Infants of women with intellectual disabilities have an increased risk of low birth weight and of being small for gestational age (Greenwood, 2013). The rate of sexual assault among women with intellectual disabilities is seven times higher than that of those without disabilities. All crimes like abuse, violence and SRH needs for women with ID are especially overlooked and understudied (Greenwood, 2013). Women with ID deserve enough skills and knowledge to express positive attitudes regarding their bodies and sexuality, value self-respect, and safe sex practice, and protect themselves from unhealthy sexual relationships. Women with ID do not get enough information regarding unplanned pregnancies, and the prevention of STIs. They are victims of sexual abuse and HIV infections because of unsafe sex practices, poor sexual education, and poverty (Kramers-Olen, 2016). According to a study in Bangladeshi, people with disabilities were 14 times more likely to seek treatment than other people (Gudlavalleti, 2018). Moreover, another study on the double burden: barriers and facilitators to socioeconomic inclusion for women with disability in Bangladesh reported that the current barriers to socioeconomic inclusion for women with disability living in the community in Bangladesh are exclusion from formal education, exclusion from the workforce, exclusion from

public facilities, exclusion from marriage and increased risk of violence and exclusion from community activities and social groups (Quinn, 2016).

Furthermore, one of the key SRHR targets in the SGDs by 2030 is to ensure universal access to sexual and reproductive health-care services, including family planning, information and, education, and including reproductive health in national strategies and programs. This universal access won't be possible until women of reproductive age with intellectual disabilities can't access these services (Starrs and others, 2018). In Bangladesh, women with ID are not only lacking sexual reproductive health information, but they have difficulty accessing SRH services due to environmental barriers, attitudinal barriers, and self-stigma (Amin, 2020). In spite of the fact that they have difficulty communicating and following healthcare advice, they are not receiving sufficient attention and care from front-line health care professionals (HCP) (Brown, 2016).

Although it has expressed interest in promoting sexual and reproductive health (SRH) services for persons with disabilities, little attention has been paid to this issue by the Government, policymakers, and health care professionals till now (Amin, 2022). Though women of reproductive age with intellectual disabilities have the same rights to sexual reproductive health, they are way behind to receive their services in Bangladesh. The World Report on Disability (WHO, 2011) emphasizes that the sexual health of people with disabilities is still an under-researched area. It should be included in the research and policy agenda.

According to the UN (2006) Convention on the Rights of Persons with Disabilities, people with disabilities have the right to equal opportunities and dignity with respect to sexual and reproductive health (Kramers-Olen, 2016). But it has not been practically implemented for women of reproductive age with intellectual disabilities in Bangladesh. From Bangladesh's perspective, it is very crucial to conduct a study on sexual reproductive health for women of reproductive age with ID. There are also gaps in SRH policies and practices for women with ID. So, the aim of this study is to explore sexual and reproductive health issues and needs, identify individual factors influencing sexual reproductive health, understand issues related to health care providers influencing sexual reproductive health, and explore the environmental factors influencing sexual reproductive health for women of reproductive age with intellectual disability (ID) in Bangladesh. The findings of this study will be helpful to raise awareness about sexual

reproductive health issues and the needs of women of reproductive age with intellectual disabilities in the community and among health care professionals of Bangladesh. In addition, it will inform public policies and programs supporting women of reproductive age with intellectual disabilities and their families in Bangladesh.

1.3 Objectives

1.4.1 General objectives:

The overall objective of the study is to understand sexual and reproductive health needs for women of reproductive age with mild to moderate intellectual disability (ID) in Bangladesh, in order to create awareness in the community, among health care professionals as well as to inform the public policies and programs about supporting women with ID and their families in Bangladesh.

1.4.2 Specific objectives

- ✓ To explore sexual reproductive health issues in women of reproductive age with ID
- ✓ To identify individual factors influencing sexual reproductive health in women of reproductive age with ID
- ✓ To understand issues related to health care providers influencing sexual reproductive health in women of reproductive age with ID
- ✓ To explore the environmental factors influencing sexual reproductive health in women of reproductive age with ID
- ✓ To make recommendations on research, intervention, and policy based on findings to improve sexual reproductive health services for women of reproductive age with ID.

Chapter 2: Methodology

2.1 Study design:

A review of the literature is performed by utilizing electronic databases like Google scholar, PubMed, and the VU Library systemically to search the information to understand sexual and reproductive health needs for women with intellectual disability (ID) in Bangladesh and other countries. Snowballing technique (within PubMed and Google Scholar) is also used for several epidemiological papers and review articles. The following 3 key search items are used: sexual reproductive health, women of reproductive age with intellectual disability, Bangladesh. The point-by-point search items are displayed in (Table 1). The researcher has searched for articles using the following search terms:

Search engines	**Keywords used alone or in combination with each other**	
PubMed, VU library, Google Scholar, Google and organizational websites (WHO, World bank, UNICEF, UN-WOMEN) for grey literature.		Sexual health; reproductive health; disability; intellectual disability; sexual reproductive health; sexual reproductive health needs; women of reproductive age; women with intellectual disability; women of reproductive age with intellectual disabilities; disability rights in Bangladesh; sexually transmitted diseases; sexual knowledge; marriage; sexual abuse; marriage; forced marriage; health care professionals;
	AND/OR	Pregnancy; contraception; period; sex; attitude; accommodation; knowledge; society ;stigma ; self-stigma; factors; prevalence; experiences; risk factors; environmental barriers ;attitudinal barriers; perception; trust; accessibility; infrastructure;
	AND/OR	Bangladesh; India; Pakistan; Nepal; Bhutan; South Asia, Lower middle-income country, LMIC;

Table 1: Search engines

2.2 Exclusion and inclusion criteria:

All literature published in English-language issued in the last 20 years (from 2000 to 2022) will be included for review to maintain the relevance of the information. Literature focused on Bangladesh is primarily considered but literature from a similar context, LMIC, and global context are also used when local studies are not found or to put the findings in the broader context.

Both quantitative and qualitative studies are considered for the thesis.

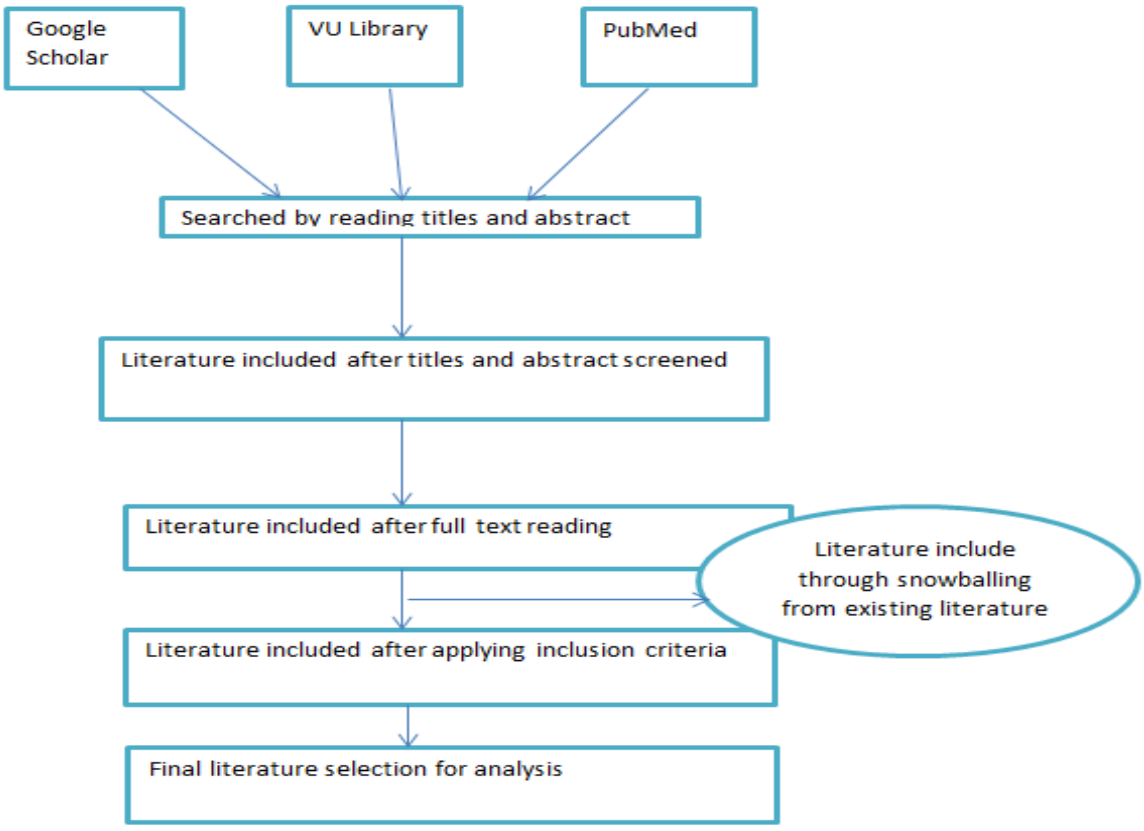

Figure 1: Search and inclusion criteria of literature flow chart

2.3 Screening and inclusion:

The articles are screened manually after reading the titles, abstract, and then full text. Papers are only included if found relevant after screening. After that, articles that don't meet the exclusion

and inclusion criteria are excluded. The rest of the articles and reports are then selected for final review.

2.4: Limitation of the study

This study has some limitations. In the Asian region including Bangladesh, few studies have been published on women of reproductive age with intellectual disabilities and sexual reproductive health needs and services. That is why enough information did not find in Bangladesh and the nearest countries. Most of the literature added in this study is from developed countries.

2.5: Dissemination of the findings

Results will be disseminated to the Ministry of Health (MOH), the District Health Office (DHO), and organizations that work for women of reproductive age with intellectual disabilities in Bangladesh. Dissemination of information will be organized through workshops, conferences, and meetings for relevant stakeholders as well as media publications including blogs, articles, and journals. Soft copies will be accessible to universities and learning institutions.

2.6. Conceptual framework:

The results were investigated by using the conceptual framework of reproductive health in the context of physical disabilities (Kalpakjian, 2020). The researcher used this framework because it helped to find answers to all research objectives. This framework was used in research to understand reproductive health for women with physical disabilities. The initial conceptual framework (Fig.2) was defined by six major concepts that all intersect with reproductive health issues and with each other in some way, reflecting the complexity of the reproductive health context of physical disabilities. The six major concepts are reproductive health issues, knowledge about reproductive health, communication about reproductive health, self-advocacy & identity, reproductive health environment, and relationships.

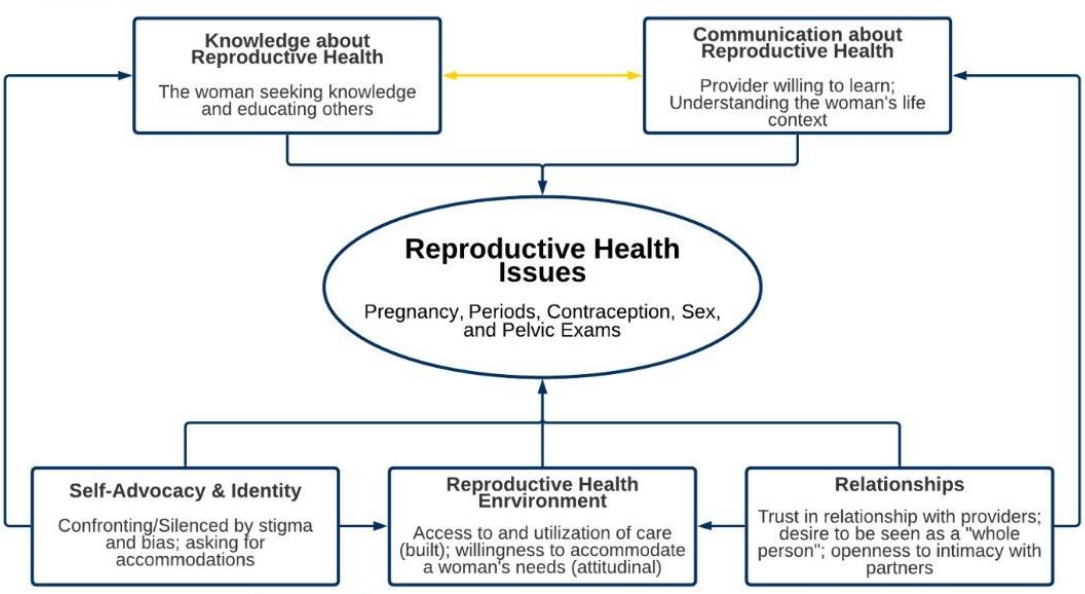

Figure 2: The conceptual framework of reproductive health in the context of physical disabilities (Kalpakjian, 2020)

In order to fit with the objectives and purpose of the study, this conceptual framework has been adjusted. In the previous framework, the core component of reproductive health issues represented 5 SRH issues including pregnancy, periods, contraception, sex, and pelvic exam. But the adjusted one only represents 4 including pregnancy, periods, contraception, and sex. The pelvic exam is not included because it is not related to intellectual disabilities. One component named relationships has been removed in the adjusted one because it is more related to physical disabilities. The way this component was used in the conceptual framework for physical disabilities is more about how women with physical disabilities feel and perceive about their partner, peers, health care providers. Women with ID have limited abilities to comprehend, judgment and lack of intellectual skills, this is why this component is adjusted. The adjusted framework (Figure.3) will provide information regarding 5 components including reproductive health issues, knowledge about reproductive health, and communication about reproductive health, reproductive health environment, and self-advocacy in combination with identity.

2.6.1. Component 1: Reproductive health issues:

Reproductive health issues are the core component of this conceptual framework. This component explains the sexual reproductive health needs of women of reproductive age with

intellectual disabilities. The central component gives information about reproductive health issues including pregnancy, periods, contraception, and sexual behaviors (Kalpakjian, 2020)**.** Pregnancy is a complex issue itself. For women of reproductive age with ID, it is difficult to make a decision about it because of cognitive issues. The menstrual cycle is a common thing every woman needs to face every month. It is very important to know how women of reproductive age with ID are managing these periods, do they need any support for that, and what kind of methods are they using. Contraception methods are also important to understand in the case of women with ID. This part also focuses on descriptions of sexual encounters regarding women of reproductive age with ID.

2.6.2. Component 2: Knowledge about reproductive health:

There is a lack of knowledge among health care providers about disabilities and their sexual reproductive health needs of them. On the other hand, women of reproductive age with ID may not have knowledge and information about SRH services. This section will discuss about limited competency of health care providers and their knowledge about SRH services. In addition, it will also provide information about the lack of SRH information among women of reproductive age with ID (Kalpakjian, 2020).

2.6.3. Component 3: Communicating about reproductive health:

This frame provides information on how women of reproductive age with ID communicate with their health care professionals about their issues and needs about SRH. There are several factors influencing communications about reproductive health issues with healthcare providers including women's hesitation to start conversations with healthcare providers. This component also reveals how the health care providers understand women with ID's life context and their willingness to learn about ID and SRH (Kalpakjian, 2020).

2.6.4. Component 4: The reproductive health care environment:

This portion talks about the barriers to accessing sexual reproductive health services for women of reproductive age with ID. For example, environmental barriers include the availability of services and inaccessible information, and attitudinal barriers include negative attitudes from health care professionals and others (Kalpakjian, 2020).

2.6.5. Component 5: Self-advocacy and identity:

Self-stigma is most often faced by women of reproductive health with ID in terms of sexual reproductive topics. Because of this, they hesitate to talk about pregnancy, sexually transmitted infections, birth control, and menstrual suppression. This frame will inform us about this particular matter (Kalpakjian, 2020

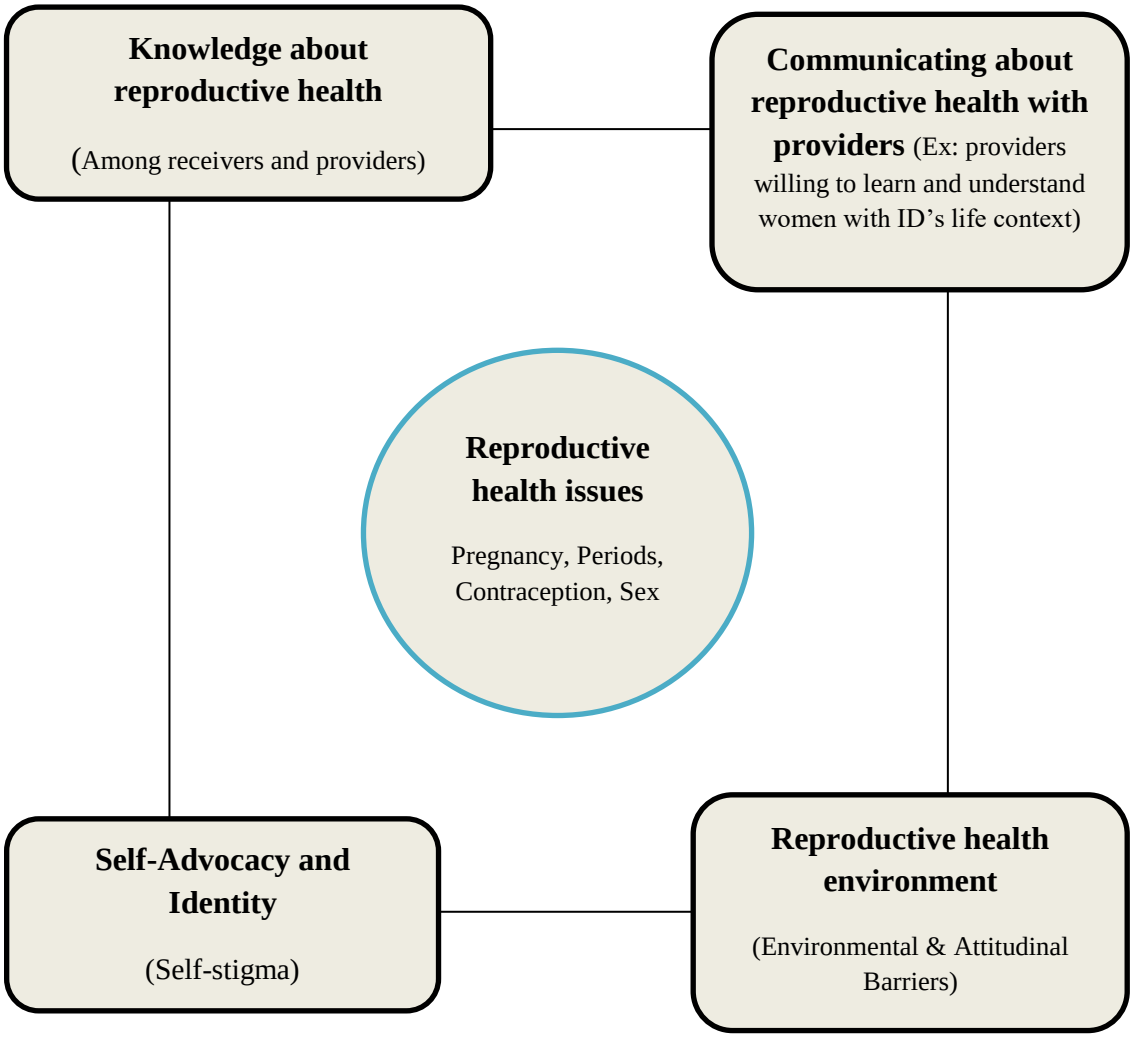

Figure 3: Adjusted conceptual framework of sexual reproductive health in the context of women of reproductive age with intellectual disabilities (Kalpakjian, 2020)

Chapter 3: Result

The adjusted conceptual framework for women with intellectual disabilities was used for the literature review to complete the result section. For literature searching, the researcher looked for information in Bangladesh and other neighborhood countries including India, Nepal, Pakistan, Bhutan, and to other countries respectively. These neighborhood countries share almost the same cultures, religions, food, beliefs, and values on SRH issues. In South Asian countries including Bangladesh, there is a shortage of data on sexual reproductive health in women of reproductive age with intellectual disabilities. That's why the researcher also included a few literatures about sexual reproductive health issues and services related to women with disabilities where it is relevant. After literature reviews, the following information has been found:

3.1. Reproductive health issues

3.1.1. Pregnancy

Women of reproductive age with ID are getting married, pregnant, and having children and this number is increasing day by day. There are several studies found that provided information about the pregnancy of women of reproductive age with intellectual disabilities. But no significant data was found in Bangladesh about pregnancy-related issues for women of reproductive age with intellectual disabilities. One study in South India showed that prenatal, natal, and postnatal care needs are greater for women with disabilities than for other segments of the population. Women with and without disabilities had no statistically significant differences in utilization of antenatal care and pregnancy outcomes in south India, according to that study. Furthermore, this study showed a significantly lower rate of pregnancy among women with disabilities (36.8%) than among women without disabilities (X2 –16.02; $p < 0.001$) (Gudlavalleti, 2018).

Moreover it has been reported that such as lower-middle-income come countries, no interventions are found to promote maternal health and family planning for women with disabilities in general (Mohosin, 2022). In a quantitative study in south India, it was found that women with ID experience diabetics (OR: 19.3, 95% CI: 1.2- 313.9) as well as depression (OR: 9.5, 95% CI: 2.2-40.8) during pregnancy periods. It was also reported in that study that the differences between pregnancy outcomes in women with ID and without ID occur due to two main causes: 1. complications of disabilities affect the reproductive health of women and 2. the

lack of knowledge of health care providers regarding the specific needs of women with intellectual disabilities (Tara, 2020). A cohort study utilizing antenatal clinic records completed in Australia reported 57 (6.7%) pregnant women with ID out of 878 pregnant women in their study. The study participants with ID showed many pregnancies health-related problems including gestational diabetics, high rate of pre-eclampsia (odds ratio=2.85), newborns who are more likely to have low birth weights (odds ratio=3.08), common delivery complications (induced labor, precipitous labor [birth after <3 hours of regular contractions], prolonged labor [>20 hours for first-time mother, >14 hours otherwise] (Rubenstein, 2020), more frequent admission to neonatal intensive care facilities (odds ratio=2.51) (McConnell, 2008), and poor breastfeeding (Goldacre, 2015).

In population-based studies Among U.S. women with intellectual disabilities, it was reported that women with intellectual disabilities were more likely to have preterm deliveries, low Apgar scores, cesarean deliveries, and longer delivery-related hospital stays, and were less likely to breastfeed at discharge from the hospital (Mitra, 2018). A population-based retrospective cohort study (from 2002 to 2009) among Massachusetts residents found that 54.8% of women with ID had at least one emergency department (ED) visit during pregnancy compared to 23% of women without ID (Mitra, 2018).

Another study from the archived dataset of the Oxford record on 217 births from mothers with ID out of 245007 births concluded that women with ID get pregnant at a young age and most of the time they are unmarried at pregnancy time (Goldacre, 2015). There was no significant association between women with intellectual disabilities and maternal weight, and cesarean section or forceps delivery. According to Matin, 2021, women of reproductive age with ID also become pregnant because of sexual abuse. It was also mentioned that they are being targeted for sexual abuse because they are considered sterilized and have lower fertility rates (Eric, 2022). In a study in Sweden, it was mentioned that women with intellectual disabilities are unfit for being a mother and they are considered a risk group for pregnancy. But also, their pregnancies had been seen as mistakes (Höglund, 2013).

3.1.2. Periods

Menstrual symptoms including abdominal or pelvic cramping, lower back pain, headache, and fatigue are experienced by women with intellectual disabilities and are similar to those of women without intellectual disabilities; however, societal and institutional influences affect their interpretation of and attitude toward menses. Managing menstrual time is very challenging for women with ID and there are very limited data available about it. According to Yueh-Ching 2008, the autonomy and choices of women with ID are limited. One study was done in England with women aged between 14 to 55 years old whereas 3% of study participants were Asian and 15% (66) women had mild ID and 36% (156) had moderate ID. They reported that they didn't revive the information about how to manage menstrual care. They need caregivers to manage period and from them 96% caregivers were female, 4% were male and 55% were paid and 45 % were related to the person. The level of care also differs by the extent of ID and level of independence. But no significant relationship was found between the intellectual disability level and the effort to teach about menstrual care. It was also found that women with mild ID were aware of societal norms related to privacy around menstruation. Women with severe or profound IDs received more information about periods than mild or moderate ID (Rodgers, 2005).

A study done in India on a menstrual pattern among women with intellectual disabilities found that more than half (65%) of the women with intellectual disabilities have menarche at the age of 12-14 years, for 10% of girls it started at the age 15-17 year and for 8% girls age 09- 11 year. However, the average age of menarche is 13-14 years old. This study also mentioned that most females with ID can manage their menstrual period independently and they do not have any medical or related issues (Nazli, 2016).

Women with ID have a lack of understanding about menstrual management and it takes longer for them to learn the required steps to manage periods properly. They have difficulties understanding how to put pads in appropriate places, how to react when they see blood on clothing, how and where to inform others about their menstrual information to others (Tracy,2016).

In a cross-sectional, questionnaire-based study that recruited 1,152 caregivers in welfare institutions in Taiwan, it was reported by caregivers that women with ID have a lack of

understanding of issues related to menstruation including sex education, menopause, and reproductive health services (Lin, 2011).

In 2008, Willis conducted one study on mild to moderate intellectual disabilities about their understanding and knowledge of menopause in Scotland and his study concluded that they have very limited knowledge on this subject because of limited accessible information about menopause and paucity (Willis, 2008).

Though there is a lack of information about periods among women with intellectual disabilities in Bangladesh, the information collected from other countries by literature review shows that there is a lack of awareness and limited knowledge on menstruation among women of reproductive age with intellectual disabilities and caregivers.

3.1.3. Contraception

According to the existing literature, women of reproductive age with ID receive very limited information about the basic knowledge of contraception and reproduction. But little information has been found in LMICs, particularly on women with ID regarding contraception. One research was completed in India by using secondary data analysis from the dataset of the 2010-2011 Annual Health Survey on women with disabilities (238,240 women aged 15-49 years). It was reported that 73.0% of women with disabilities use modern contraceptives (OR 0.87, 95% CI: 0.78, 0.95) and 57.7% of women with disabilities use sterilization (Casebolt, 2022). There are very few women with ID who visits the hospital on their own and none receive any accessible information about contraception (Michelle, 2009). They are less likely to use contraception which leads to getting a higher rate of sexually transmitted infections. These complications also depend on the severity of intellectual disabilities. Women with mild to moderate intellectual disabilities develop the same sexual interests and desires as women without disabilities, according to a study (Abells, 2016).

A study conducted in the Netherlands on the contraceptive use of women with ID concluded (15 to 59 years old) that they use contraception for some specific reasons including menstruation problems, preventing pregnancy, and managing behavioral problems. Among them, 78% of participants took pharmacological contraceptive methods, 20% of them used underwent surgical contraception and the rest of them used both. No significant association was found between

levels of ID, and age with users of different contraception. This study informed that the decision-making part about contraception cannot be always taken by the women with ID because they don't have enough knowledge about methods of contraception and its benefits. This decision-making process also depends on the severity of ID and their level of understanding of contraception use. In this study, the request for use of contraception was made by the physicians and parents (Valk, 2011).

Another study done on the use of contraception of women with ID aged 18 to 46 years old in Belgium found the following information (Fig:3) about contraception among women with ID. (Servais, 2002).

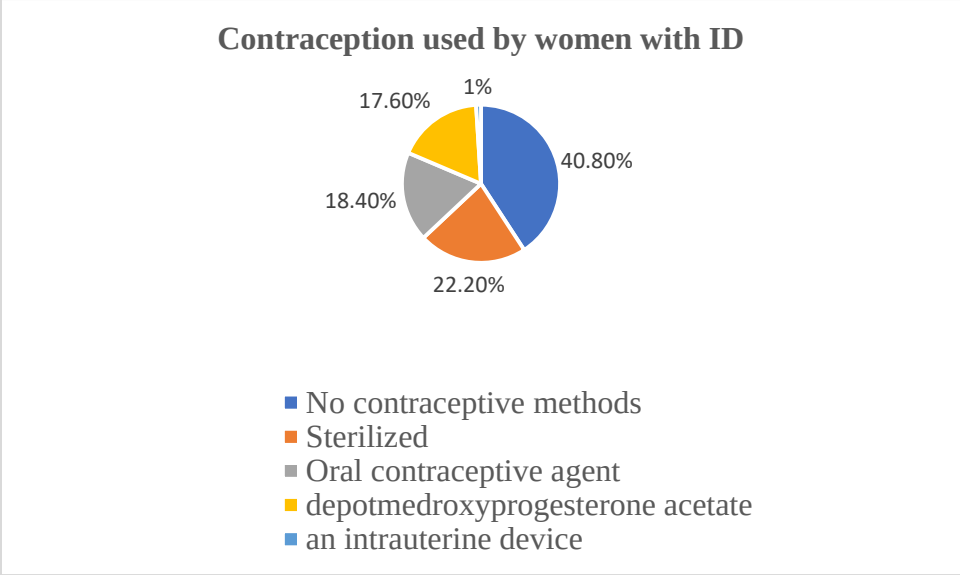

Figure 4: The use of contraception of women with ID aged 18 to 46 years old (Servais, 2002).

3.1.4. Sex

Though there is no evidence found in Bangladesh regarding sexual behavior among women with intellectual disabilities, many studies showed that the lack of knowledge about sexual education is one of the main obstacles to having a healthy sexual life. A systematic review of qualitative studies conducted on sexual health concerns in women with intellectual disabilities in 2018 found much important information regarding this issue. There is no specific place mentioned in this study. According to this study, women of reproductive age with ID have difficulty finding the desired partner for them. They are also being exposed to sexual abuse by their relatives,

caregivers, and colleagues in public places. For example, workplaces, public transportations, schools, and institutions. Women with ID described it as forced kissed, inappropriate touch, and rape. Police treated them negatively when they asked for help from them. Besides this, they face difficulties to access information about sexual health due to limited communication skills including lack of eye contact, and limited cognitive capacities. Due to cognitive impairment and lack of social interaction, many of them can't express their feelings about sexual issues and sexual needs and face difficulties to recall memories about sexual topics, understanding sexual intercourse, time of ovulation, sperm mobility, and difficulty in developing a sexual relationship with men (Matin, 2021).

Women of reproductive age with intellectual disabilities have a poor understanding of sexual activities. There is very little information found regarding sexual activities in women with intellectual disabilities. Many misconceptions exist about this issue like as having sexual relations with women with ID is illegal and they should not engage in sexual relationships (Eastgate, 2011). Though women with ID have the same or greater risk of getting sexualy transmitted diseases (STD) than people without disabilities, there is a shortage of literature on the prevalence and incidence of sexually transmitted diseases among them. One study in India estimates reveals that 3% of males and 5% of females receiving special education are treated for STDs. In addition to this, in India, women with ID are significantly less likely to have an STD diagnosis (Schmidt, 2019). Understanding the sexual behaviour of women with intellectual disabilities is very important, but due to a lack of data, it is challenging to understand this issue.

3.2: Knowledge about sexual reproductive health

3.2.1. Knowledge of health care professionals about sexual reproductive health

Health care providers' attitudes towards sexual reproductive health in women with intellectual disabilities are not well studied in Bangladesh. There is no specific data about sexual reproductive health for women with intellectual disabilities. In Bangladesh, however, a quantitative survey found some information about sexual reproductive health for people with disabilities in general. People with disabilities with limited knowledge of sexual reproductive health often face discrimination, social barriers, attitudinal barriers, and rude behavior from practitioners (Mohosin, 2022).

In India, a study conducted by Casebolt, 2020 reported that health care professionals are not aware of the sexual reproductive health needs of people with disabilities and they do not get enough training on SRH services. Craig reported in 2022 that health care professionals have a lack of knowledge, lack of training, lack of awareness poor collaboration between staff, not enough guidelines, and, poor confidence and competence regarding SRH services for people with disabilities (Craig, 2022). A study concluded in the UK that a lack of knowledge and understanding about intellectual disabilities leads to a poor attitude toward them including an abrupt way of speaking (Doherty, 2020). In a literature review (271 articles) studies in lower-middle-income countries, reported that health care providers feel uncomfortable discussing SRHR because they are confused about how to approach women with ID. In addition to this, service providers lack understanding about the extent of abuse experienced by women with ID due to a lack of training (Tara, 2020).

Moreover, a study in the USA stated that health care professionals don't receive any training in caring for pregnant women with ID (Amir, 2022). Höglund conducted one study in Sweden about midwives' experiences of caring for women with ID. His study findings are presented in the table

S/N	Participants	Comments
1	81.5% midwives	had the experience of caring for women with ID
2	47.3% midwives	had not received any education about pregnancy and delivery of women with ID
3	95.4% midwives	requested evidence-based knowledge of women with ID in relation to childbirth
4	69.7% midwives	thought that women with ID cannot satisfactorily manage the mother role
5	35.7% midwives	opined that women with ID should not be pregnant and give birth at all

(Höglund, 2013).

Table 2: Health care professionals experience in caring pregnant women with ID

3.2.2. Knowledge of women of reproductive age with ID about sexual reproductive health

There is no exact data found on literacy level on women with intellectual disabilities about sexual reproductive health. But it has been reported by UNESCO that 99% of girls with disabilities are illiterate in developing countries (Mohosin, 2022).

In a literature review study, it has been indicated that lack of education on sexuality and reproductive health is one of the main reasons why women with ID experience inappropriate sexual behavior, and vulnerabilities to abuse (Abells, 2016). Moreover, they realize they are pregnant lately because they are unfamiliar with the signs and symptoms of pregnancy. That is why it causes many pregnancies related complications, unwanted pregnancies, and abortions (Abells, 2016). According to Matin 2021, the lack of sexual knowledge is the leading cause for women with ID to experience unsafe sexual relationships. They have very little knowledge of contraceptive methods, sexual behaviors, sexual abuse, and the process of sexual intercourse and pregnancy. It was also mentioned in one research that women with ID confronted difficulties to discuss, explore, and specify their sexuality-related issues in order to have language, speech, and cognitive disorders. Even some women with ID have fewer opportunities to have and maintain an intimate relationship (Matin, 2021). Women with ID face obstacles in obtaining informed consent for participation in medical procedures, understanding information communicated by the specialists, and the capability of using public information, such as invitations to free health check-ups (Parchomiuk, 2018).

In the Philippines, a study concluded that health care providers have limited understanding of the needs of women with disabilities, their rights regarding sexual reproductive health, and other specific factors such as abuse and violence due to lack of training in this area and inadequate access to resources (Lee, 2015). In Australia, a study reported that women with mild ID have correct information about periods, time of ovulation, and sperm motility (Eastgate et al, 2011). Women with ID lack knowledge about the basics of a male's body and have no idea about sexual relationships with men (Frawley, 2016). Matin also found in his study that women with ID do not receive any school-based sexuality education and they are let off from the classroom during sexuality education lessons. In one study health care professionals identified that women with ID do not undergo regular breast screening due to a lack of knowledge and limited understanding though they have the same rights as other women to access breast screening services

(Mcilfatrick, 2011). Moreover, Women with ID do not have enough skills and knowledge to express positive attitudes regarding their bodies and sexuality, value self-respect, and safe sex practice, to protect them from unhealthy sexual relationships, unplanned pregnancies, and the prevention of STDs (Kramers-Olen, 2016).

3.3: Communicating about reproductive health

There is no study found in Bangladesh about communication about sexual reproductive health between health care providers and women with intellectual disabilities. Good communication between health care providers and women with ID is the key to building trust and getting fruitful treatment. One study found that health care providers don't have enough awareness about the communication difficulties in women with ID that results in miscommunication and wrong diagnosis (Tara, 2020). According to Breau 2021, health care professionals have told women with intellectual disabilities and their families that breast and cervical cancer screening is not mandatory for women with ID. This may reflect negative attitudes towards this group (Breau, 2021). Moreover, because of poor communication women with ID have lower expectations and feel dissatisfied about health care providers (Doherty, 2020). One study in New England suggested that health care providers also hesitate to talk about sexual and reproductive health with women with intellectual disabilities and they underestimate the ability of decisions making regarding this. Health care providers rely on caregivers (Nicole, 2020) which may lead communication gap between women with ID and heath care providers.

3.4: The reproductive health care environment

3.4.1: Environmental barriers

A study published in Bangladesh in 2020 analyzing the situation on sexual and reproductive health care services of persons with disabilities reported that there are some barriers to accessing SRH services in Bangladesh including the high cost of treatment, improper health care infrastructure, and inadequate information about service availability regarding SRH (Das, 2020). Another explanatory sequential mixed-methods design study on a total of 5000 persons with disabilities In Bangladesh concluded that people with disabilities get misinformation, experience mistreatment by SRH health care professionals, and distrust SRH services which discourages them to seek SRH services in the future (Mohosin, 2022). A national wide mixed method study

in Bangladesh concluded that people with intellectual disabilities face barriers to establishing their rights to access SRH services including transportation hurdles, high cost of treatment, lack of information about SRH services availability, inaccessible and disabled-friendly health care facilities, and inadequate family support (Amin, 2020).

An investigation in South India identified a number of barriers to accessing health care services for women with disabilities, including distance to a health facility, a lack of infrastructure and equipment, cost of care, lack of awareness about the availability of services, and transportation (Gudlavalleti, 2018). Environmental barriers for persons with disabilities in Pakistan are transportation, as well as outdoor and indoor environments in which health services are provided. People with disabilities in Pakistan have inadequate access to reproductive health care services and insufficient knowledge about prevention measures for tuberculosis, hepatitis, and HIV/AIDS (Gudlavalleti, 2018). These environments include buildings, waiting areas, washrooms, examination tables, beds, etc. Among the main environmental barriers reported in Nepal were transportation and attitudes of family members and the community (Gudlavalleti, 2018).

A major concern for people with disabilities is the cost of health care. In Bangladesh, it was found that individuals with disabilities reported significantly higher out-of-pocket payments in a recent study analyzing data from the Bangladesh Household Income and Expenditure Survey. Afghanistan showed similar observations (Gudlavalleti, 2018). According to a study conducted in India, people with disabilities face significantly increased barriers to accessing health care, including ignorance regarding the availability of services, transportation, and costs (Gudlavalleti, 2014). One study conducted in Africa concluded that people with disability face environmental barriers while accessing SRH services. At the hospital, they have a lack of disability-friendly washrooms, delivery/labor wards, to lack of effective interaction and communication systems, lack of SRH information/resources in healthcare settings, lack of privacy and confidential services, lack of adaptation of health information to suit, unfriendly HIV/AIDS education materials, longer waiting times, and lack of knowledge or limited capacity of staff on persons with disabilities SRH issues (Ganle, 2020).

3.4.2. Attitudinal barriers

Negative attitudes are a major barrier to optimal sexual health for people with intellectual disabilities. Women with ID face negative attitudes from community, family, and health care professionals (Thompson, 2014). In Bangladesh, people with disabilities who seek sexual reproductive health services experience disrespectful and negative attitudes from health care professionals (Mohosin, 2022). A lack of appreciation by healthcare providers for the needs of people with disabilities, ill-treatment by providers, and negative perceptions by providers have been reported as attitudinal barriers to access health care services in South Asia (Gudlavalleti, 2018). In Nepal, it was found that providers' attitudes towards persons with disabilities were negative and they lacked knowledge and skills about how to provide services to them (Devkota, 2017).

A study concluded that intellectual disability is related to demon possession, being cursed, or the product of witchcraft and it is the result of divine punishment for sin. It is possible that women with ID are unaware of their sexuality and are therefore perceived as hypersexed. Sexually active women with ID will have children with disabilities (Klaudia, 2021). Researchers have found that people with disabilities experience discrimination, lack of cultural sensitivity in service delivery, negative attitudes from health care professionals, stigma, isolation, and social barriers (Raghavan, 2004). Both individuals with ID and family members are victims of stigma and its effects on their psychological wellbeing (Ali, 2012). In some studies, it has been stated that because of stigma and bias women with ID feel shy to discuss sexual reproductive health-related topics including intercourse, sterilization, etc. In addition, some studies indicated that parents and careers of women with ID feel shy to provide sexual guidance for them. Because of a lack of privacy and negative attitudes toward their sexuality, some women with ID hide their sexual experiences and consensual sexual contact (Matin, 2021).

Cultural factors are another issue regarding SRH in Bangladesh. Secondary and higher secondary schools in Bangladesh face considerable barriers and taboos regarding the sharing of information about sexuality due to socio-cultural and religious factors (Bhuiyan, 2006). Premarital sex and sexual interactions between boys and girls are stigmatized in Bangladesh. They are unlikely to be discussed or provided with information about SRH due to its status as a taboo subject. Despite restrictions from family and community surrounding romantic relationships, Reeuwijk & Nahar

found that Bangladeshi boys and girls engage in sexual interactions, including kissing and hugging (Nahar, 2013). Rather than addressing the root causes of sexual harassment, discussions focus on how girls should behave and dress in order to avoid unwanted attention from men and boys. SRHR topics are uncomfortable for both teachers and students to discuss in classrooms and also the fear of giving a wrong impression of them makes adolescents reluctant to talk about their sexuality in the classroom (Sabina, 2016).

3.5: Self-advocacy and Identity

Women with intellectual disabilities are one of the most stigmatized groups in society. Generally, women with disabilities are stigmatized to access reproductive health services which lead to a higher rate of intimate partner violence and sexual abuse by relatives (Ando, 2017). Women with mild intellectual disabilities suffer from low self-esteem. This is because they have a feeling that they are different than others and they don't have a husband, own home, and children. Many women with mild ID reported that they felt different because of stigmatization, abuse, and exploitation (Taggart, 2010). It has been found in one systematic review that stigma related to people with intellectual disabilities can negatively impact psychological wellbeing, including lower self-esteem, negative self-evaluations, negative social comparisons, and psychiatric symptoms (Ali, 2012). There is evidence of stigma among women with disabilities in Indonesia because of social participation restrictions that lead to lower education, income, and marriage prospects (Zaal-Schuller, 2010). Women with intellectual disabilities have poor self-efficacy, self-stigma, limited sexual knowledge, and misconceptions about sexuality and reproductive health which leads them to have unsafe sexual practices (Schmidt, 2019). A literature review study on challenges in providing reproductive and gynecologic care to women with intellectual disabilities concluded that due to intellectual limitations and social stigma, women with ID are forced to undergo sterilization and end up facing psychosocial challenges, due to financial instability, parenting difficulties and inadequate social support (Singh, 2022). One study reported that fear and feeling of being embarrassed are also obstacles to accessing health care services for women with ID. Women with ID are not getting involved in decision-making about them. All the decisions are made by their families, careers, and health care providers which makes them feel low (Doherty, 2020).

Chapter 4: Discussion

Women of reproductive age with intellectual disabilities have the same rights regarding sexual reproductive health as women without disabilities. Although Bangladesh lacks research, information, and evidence about sexual reproductive health for women with intellectual disabilities, neighboring countries and other developed countries provided much information with a clear picture of the barriers women face regarding sexual reproductive health services. Bangladesh does not have the opposite situation. Even women of reproductive age with intellectual disabilities may suffer more because of stigma, and incompetence among health care workers to understand the needs of such women let alone respond adequately to those needs. The formal public health system in Bangladesh provides few services for common sexual and reproductive health problems such as white discharge, fistula, prolapse, menstrual problems, and urinary tract infections (Sabina, 2016). But no initiative has been taken yet to serve women with disabilities regarding sexual reproductive health issues and needs. By utilizing this adjusted conceptual framework (Kalpakjian, 2020) this study answered all the objectives.

4.1: Sexual reproductive health issues and needs in women of reproductive age with intellectual disabilities:

Women of reproductive age with ID have an increased risk of pregnancy complications and face a significant risk of poor pregnancy outcomes. Though there is very limited information about pregnancy in women of reproductive age with intellectual disabilities, other neighborhood countries provided a clear picture regarding this issue. Based on the findings of the literature review, it is found that women of reproductive age with intellectual disabilities also experience pregnancy in the same way as women without disabilities experience. However, they face more complications during pregnancy than women without intellectual difficulties including gestational diabetics, prolonged labor during delivery, a high rate of pre-eclampsia, depression, and poor breastfeeding (Rubenstein, 2020; McConnell, 2008; Goldacre, 2015).There is a lack of awareness and adequate information about SRH for women with ID in general. Though women with ID are considered unable to get pregnant, sterilized, and have lower fertility rates, unfit to be a mother by society (Höglund, 2013), but it is interesting that other studies also concluded that many pregnancies among women with ID are happening because of sexual abuse (Matin, 2018; Eric, 2022).

For women with intellectual disabilities, menstrual problems are another concern. There is a lack of awareness and availability of information about periods for women with ID. The studied literature showed that they have very limited information because of limited opportunities to know about it. Because of their poor cognitive skills (Shogren, 2010), it takes more time for them to learn how to manage their menstrual time including how to manage this situation takes a long time including putting pads in appropriate places, how to react when they see drops of blood on clothing, and how and where to inform about their menstrual information to others (Tracy, 2016). Women with ID also need support from caregivers to manage this time (Rodgers, 2005). Though one study showed us that women with mild to moderate intellectual disabilities have a good understanding and knowledge of menopause, this study was done in Scotland which is a high-income country with high-quality care systems in place for women with ID (Willis, 2008). We do not have any information regarding knowledge and understanding of mild to moderate intellectual disabilities in Bangladesh or other lower-middle-income countries. More research on access to menstrual information and practices for women with intellectual disabilities in Bangladesh is needed. Guardians and/or the caregivers of women with ID need to be educated properly about how to manage menstrual periods for women with ID. Besides this, negative attitudes from health care professionals, and related stigma that exist means that women with ID are minimally educated about this issue. In addition to this, a lack of disability-friendly washrooms, delivery/labor wards, a lack of effective interaction and communication, lack of SRH information/resources in healthcare settings, a lack of privacy and confidential services, and a lack of appropriate and adapted health information (Amin, 2020; Gudlavalleti, 2018; Ganle, 2020) are pushing them away to stay behind.

In the case of contraception, it has been found that women with ID have very limited information because of limited opportunities to know about it. Due to this, they may have increased risks of contracting sexually transmitted disorders. In addition to the lack of information as well as lack of opportunities to get information, they could have – due to their mental capacity- limited decision-making capacity (Shogren, 2010) about contraceptive options. This is not only happening because of limitations in cognitive skills in women with ID, but also due to a lack of knowledge and lack of training of health care professionals (Gudlavalleti, 2018; Devkota, 2017; Mohosin, 2020). In addition, there is a lack of awareness among health care staff about the specific attention that needs to be given to women with ID, there is often poor collaboration

between staff, guidelines may be absent and poor confidence and competence regarding SRH services among health care professionals. Moreover, in lower-middle-income countries, health care providers feel uncomfortable discussing SRHR because of a lack of understanding of the characteristic intellectual disabilities. It is very important for health care professionals to get guidelines about sexual reproductive health services, especially for women with intellectual disabilities, so that they can provide care for women with ID properly and give them enough information.

Inappropriate sexual behaviors are another SRH issue for women with ID due to a lack of sexual education. In many societies, people lack of awareness and understanding of the sexual abilities of women with ID. Due to self-stigma, poor self-efficacy (Ali, 2012), misconception about appropriate sexual behaviors (Eastgate, 2011), women with intellectual disabilities may be exposed to sexual abuse (Taggart, 2020; Ali, 2012). In addition, due to limited intellectual abilities, lack of education, and communication skills, women with ID do not seek out relevant information and guidance for sexual reproductive health (Matin, 2021).

Information about sexual reproductive health issues and the needs of women with intellectual disabilities are not enough in the literature. They have way more issues and needs that are still yet to be investigated. Based on the literature review can say clearly that women with ID go through the same reproductive phase as like every other woman with or without disabilities. Women of reproductive age with intellectual disabilities in Bangladesh lack proper sexuality education which may increase the risk of unwanted pregnancies, STDs, and HIV/AIDS. Comprehensive sexuality education (CSE) is necessary for them to learn about SRHR and to develop adequate self-esteem. They need every single treatment, care, and support from the community, family, society, and health care professionals. They need information about pregnancy, contraception, family planning, menstruation management, and sexual activities. Even they need extra care because of their limitation in understanding, processing information, and memorizing. Women of reproductive age with intellectual disabilities need to get sufficient and specific adapted information and education in school and at home about the proper management of menstrual periods, available contraceptive options, pregnancy time, and appropriate sexual behaviours.

4.2: Individual factors influencing sexual reproductive health in women of reproductive age with Intellectual disabilities:

There are some individual factors as well that influence sexual reproductive health in women of reproductive age with intellectual disabilities. In addition to sexual reproductive health issues and needs, identifying individual factors influencing sexual reproductive health in women of reproductive age with ID are important to explore. For example, women with mild intellectual disabilities suffer often low self-esteem and due to this, they feel self-stigmatized (Schmidt, 2019; Taggart, 2010). Women with ID may have low self-esteem and self-stigma because they considered themselves differently from others. Most of the cases, they don't have a husband or own home, or children and they are victims of abuse and exploitation (Taggart, 2010). This is because of a lack of education, lack of information, and lack of awareness among the general population about intellectual disabilities and sexual reproductive health. Because of being intellectually disabled, women with ID lack communication skills, problem-solving skills, and comprehension which lead them to process information about others (Shogren, 2010). For example, they know about their pregnancy late because they are not aware of the signs and symptoms of pregnancy. Guardians and/or caregivers of women with ID feel shy to talk about SRH topics because of lack of privacy and negative attitudes towards HCP, stigma (Klaudia, 2021), and bias from society (Matin, 2021). This may lead them to hide their sexual reproductive health issues and needs (Greenwood, 2013; Matin, 2021). It has an effect on psychological well-being as well (Ali, 2012). In addition, women with ID may develop self-stigma and subsequent low self-esteem because they have negative self-evaluations, negative social comparisons, and lower education, income, and marriage prospects (Ali, 2012; Zaal-Schuller, 2010; Amin, 2020). HCP and caregivers/family do not allow women with ID in decision making for them (Doherty, 2020) which may lead to develop low self-esteem. Cultural factors are also pushing them as well as their family away to talk about their issues and needs. Women empowerment for women with ID is a crucial step to breaking the self-stigma and stigma from the community.

Poverty is another important issue to consider as individual factors influencing SRH for women with ID. Based on the findings of the literature, most of the time the treatment cost including sexual reproductive health services is very high (Amin, 2020). Besides this, they are facing obstacles to accessing SRH services including improper health care infrastructure, and

inadequate information about service availability regarding SRH in Bangladesh. In addition, people with disabilities especially women with ID are often not involved in employment; may not earn income, may not be married and yet have children and subsequent are poorer than others (Amin, 2020). This is why the cost of treatment and transportation is another issue to reach for sexual reproductive health services.

4.3: Issues related to health care providers influencing sexual reproductive health in women of reproductive age with ID:

Health care providers' attitudes are another important factor regarding sexual reproductive health in women of reproductive age with ID. Health care providers are the core point of contact with health care and women with ID. Their positive attitude is significantly crucial towards women of reproductive age with intellectual disabilities. After literature reviews, it was found that health care providers are unaware of sexual reproductive health issues, needs, and treatment to women with ID (Casebolt, 2020; Craig, 2022; Amir, 2022). Health care providers feel hesitant to talk about women with ID about sexual reproductive health and they prefer to with the caregivers about this issue (Nicole, 2020; Doherty, 2020). It has been found that health care providers do not have enough understanding to provide proper care.

In addition to this, health care providers do not have enough knowledge on the disability topic itself which leads to negative attitudes towards women with ID. It also came to light that health care professionals are unaware of this important issue because of lack of knowledge, lack of training, lack of awareness poor collaboration between staff, not enough guidelines, and poor confidence and competence (Doherty, 2020; Casebolt, 2020; Craig, 2022; Amir, 2022). Health care providers lack understanding of the pattern of intellectual disabilities as well including communication difficulties and low intellectual capacities among women with Intellectual disabilities (Lee, 2015; Doherty, 2020; Casebolt, 2020).

4.4: Environmental factors influencing sexual reproductive health in women of reproductive age with intellectual disabilities:

In spite of individual factors of women with ID and issues related to health care professionals influencing SRH in Bangladesh, environmental factors create huge barriers to access sexual reproductive health services for women of reproductive age with intellectual disabilities.

Literature review helped to find environmental barriers regarding sexual reproductive health for women with intellectual disabilities including long distance to health care services, high cost of treatment, having lack of disability-friendly washrooms, delivery/labor wards, lack of effective interaction and communication systems, lack of SRH information/resources in healthcare settings, lack of privacy and confidential services, lack of adaptation of health information to suit, unfriendly HIV/AIDS education materials, longer waiting times, and lack of knowledge or limited capacity of staff (Mohosin, 2022; Amin, 2020; Gudlavalleti, 2018; Ganle, 2020; Amir, 2022). Even those who are trying to seek help for their SRH issues, get misinformation, and experience mistreatment by SRH healthcare professionals which develops distrust of health care professionals and SRH services (Mohosin, 2022; Thompson, 2014; Devkota, 2017; Raghavan, 2004). That discourages them to reach out for SRH services later. Lack of awareness and inadequate information among the general population and HCP develop misconceptions and negative attitudes toward women with ID. That's why; HCP may not appreciate the needs of people with disabilities, and provide poor treatment. Because of a lack of awareness and understanding, people still think that intellectual disability is related to demon possession, being cursed, or being the product of witchcraft and it is the result of divine punishment for sin (Klaudia, 2021).

Chapter 5: Conclusion and recommendation

Conclusion

In Bangladesh, the very first barrier to accessing sexual reproductive health services for women of reproductive age with intellectual disabilities is a lack of information, research, evidence, and data on this important topic. There was a lack of significant evidence found on sexual reproductive health issues, individual factors on SRH, health care providers' knowledge of SRH, knowledge of women with ID on SRH, environmental barriers, self-advocacy, and identity in Bangladesh. But it is clear that women of reproductive age with intellectual disabilities experience difficulties during pregnancy time, periods, contraceptive options, and sexual behaviors. Due to a lack of awareness, and limited understanding of intellectual disabilities and SRHR, women with ID get less attention from family, society, and HCP. Besides this, health care professionals also do not have enough knowledge and guidelines about SRH services for

women with ID. In addition, environmental and attitudinal barriers prevent them from speaking up for their sexual reproductive health needs. And also, in lower-middle-income countries like Bangladesh, the word 'women' is stigmatized itself. When it comes to disability and sexual reproductive health, it is more biased end stigmatized. Women of reproductive age with intellectual disabilities are always way behind in their basic needs. They have similar rights and need to get married and get pregnant like other women of reproductive age without disabilities. But in Bangladesh, it has always been overlooked and no formal education provides about SRH for women with ID. So, it is yet to start working on sexual reproductive health for women with intellectual disabilities in Bangladesh. It is also important to provide training and educate caregivers of women with ID and health care professionals regarding SRH for better management and services to them.

Recommendations

Raising awareness in the community:

1. Raising public awareness for general people through social media and through the collaboration between GOs and NGOs regarding the importance and urgency of sexual reproductive health services for women with intellectual disabilities.

Improve health care services:

2. Health care professionals should receive mandatory training on sexual reproductive health issues, needs, and services for women with intellectual disabilities at the primary health care level.

Policy development and improvement:

3. The development of comprehensive policy guidelines and procedures is needed to manage risks and guide caregivers in facilitating the sexual experience of women of reproductive age with intellectual disabilities.

4. Develop and implement health system reform policies that promote SRHR, i.e. ensuring adequate funding, services, supplies, management, regulation, human resources training and deployment, and monitoring of SRH services for women of reproductive age with

intellectual disabilities to meet the key elements of the right to health including availability, accessibility, acceptability, and quality.

5. Develop, enhance and strengthen health system accountability for reducing inequalities and improving the quality of SRH services for women with intellectual disabilities at the national level by developing and strengthening indicators and tracking mechanisms.

Research:

6. Researchers should analyze factors related to sexual reproductive health services for women of reproductive age with intellectual disabilities including their SRH issues, needs, knowledge gap, environmental and attitudinal barriers.
7. Policy and institutional analysis should be carried out by researchers to address SRHR for women with ID.

Chapter 6: References

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