

COMPREHENSIVE SEX EDUCATION FOR YOUTH LIVING WITH DISABILITY IN  
BOTSWANA: PARENTS/GUARDIAN PERSPECTIVE IN SEROWE

**Abstract**

This qualitative study explored the need for comprehensive sex education for youth with disability which heightens their vulnerability to sexual violence. The study sought to establish the existence of comprehensive sex education for youth with disability; describe the challenges of parents/guardians with the provision of such sex education; and identify strategies for reducing the challenges faced by parents/guardians. used the purposive sampling design to collect data. Data was collected through face-to-face interviews. The findings established that participants view sex education for youth with disability to be crucial. But parents/guardians must manage communication barriers; low comprehension level; distorted information; youth reciting sexual related information in public; and external influences. Therefore, the following interventions are necessary: comprehensive sex education for parents offered through seminars and workshops for distinct groups; and promote parent and stakeholder collaboration.

**Key terms:** comprehensive sex education, youth living with disability, parents/ guardian perspective

## **INTRODUCTION**

Sex education is frequently marred by issues of morality and the content is often at the discretion of parents & educators who control their sex behavior and the possibility of sexual abuse or exploitation, and unintended pregnancies (1; 2; 3 as cited in Azzopardi-Lane, 4). It is a complex situation for children with disabilities. Although they are a sizable proportion of the youth population in every society (UN, 5) they are excluded at times from sexual related matters because of their disability and/ or misconceptions. Individuals with disability for centuries were thought to be inhuman, asexual, childish or are not fond of sex and unable to manage their sexuality (Güven&Dalgıç, 6). They were perceived as such because some do not know where, when and in which situations are sexual behaviors appropriate (Güven&Dalgıç, 6). Therefore, people's views on sexuality and disability are shaped or influenced significantly by their society. Thus, individuals with disabilities are rarely portrayed as sexual beings, an impression that demonstrates that they should not take part in day-day life which includes romance, intimacy, sexuality, and parenting (7). This is complicated by the misinformation from various sources, prompting parents and/or guardians to be the key providers of accurate information on sex behaviours (6). The lack of comprehensive sex education for youth with disability increases their vulnerability to sexual exploitation. This study, therefore, aims at assessing parents/ guardians' perspectives and provides awareness in ways of addressing the challenges & concerns they face when providing sex education to children with disability.

## **STATEMENT OF THE PROBLEM**

Globally, there are 240 million children with disabilities of which according to UNICEF (8) are at greater risk of abuse as compared to the general population. Furthermore, Bawden (9) states that an analysis involving more than 16 million young people conducted between 1990 & 2020, demonstrates that 31.7% of children with disability are twice more likely to face neglect &/ or sexual, physical, or mental abuse than children with no disability. Similarly, Treacy et al (10) reported that a study of approximately 55,000 children in Nebraska found that children with disability were four times more likely to be sexually abused than those without disability.

The accessibility of information regarding reproductive health, HIV/AIDS, human sexuality is often not disseminated or unavailable to youth with disability (UNICEF, 11); Kassa et al,12). Accordingly, the lack of comprehensive knowledge may have significant adverse

consequences, as youth with disability are deprived of the tools needed to navigate sex & relationships safely and confidently; hence they are most likely to experience sexual, physical & emotional violence (11).

Moreover, a study conducted in Ethiopia by Kassa et al (12) states that in many cases sexuality education for youth with disability is often withheld as it is assumed that they 'won't need it' and access to such knowledge 'gives them ideas. Youth with disability just like those without disability have sexual desires & needs, desire to marry & have children (13& 14). In the Sub-Saharan region, a study conducted in Malawi reported that 17.1% of 341 participants with disability reported coercive sexual intercourse (Munthali, Mvula & Ali,15). This demonstrates that the lack of sexual knowledge might lead to increased sexual abuse of youth with disabilities (de Reus et al, (16). UN (5), states that the CRPD & the 2030 Agenda for Sustainable Development offers a plan for inclusion of all persons with disabilities in all aspects of society and development, to allow them to contribute fully to the country economic development & growth. However, several countries still have not integrated individuals with disability fully in their society's activities (5).

Despite the existence of the Coordinating Office for People with Disabilities in the Office of the President to oversee concerns of people with disability in Botswana, there are some challenges. The office should spearhead the provision of sex education or be the forerunners of, especially to encourage and support Non-Governmental Organizations with necessary resources. They must ensure that parents promote educational awareness and provide sex education to their children living with disability. Even though Botswana has the National Policy on Care of People with Disabilities (Van Pletzen et al, (17), youth with disability continue to face multi barriers because Government of Botswana had not ratified the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) and accepted the Revised Disability Policy drafted of 2011 (Mukhopadhyay & Moswela, (18).

Several studies in Botswana on youth with disability focused on the inclusion of youth with disability in the education sector and vulnerability to sexual abuse. Although these studies acknowledged the need for sex education, there is, however, no study conducted regarding sex education for youth with disability, consequently, this study filled that gap. The study is vital and beneficial for the parents to know the challenges they might encounter when preparing their children with disabilities for sexual relationships and ways they could tackle sensitive topics. It is also crucial for the policy makers to admit that the disability legislation

is vital for the welfare of people with disability to improve. This study explored the importance of comprehensive sex education for youth living with disability in Botswana; describe the challenges parents/ guardians encounter in providing comprehensive sex education to their children living with disability.

## **LITERATURE REVIEW**

Fundamentally, parents have a crucial role as their children's primary sexuality educators; however, several factors including lack of knowledge, skills, or comfort, may impede a parent's successful fulfillment of that role (Stein et al,(19). It is also crucial for people to comprehend that the needs of people with disability may exceed those of their peers without disabilities due to disability-specific issues, such as learning of appropriate or inappropriate sexual behaviors (Holland-Hall & Quint, (20); as cited in Guven &Dalgıç,(6). Comprehensive sex education aims to provide accurate information about all aspects of human sexuality and helps develop skills to navigate relationships in ways that are fulfilling and safe (21). Furthermore, SIECUS (21) states that sex education creates an atmosphere of openness and reveals the truth that youth with disability are sexual beings with the same desires as others, hence promoting acceptance of differences.

In addition, Tissot (22) states that comprehensive sex education does not teach about partnered sexual activities, it is also designed to help people learn who they are and who they will become as unique individuals, including information about how bodies work, sex roles, assertiveness & rules of social interactions. Traditional sex education frames sex as dangerous and not at all about pleasure as a wellness, which is a concern for progressive sex educators such as Buston, Wright, Scott, and Deborah Tolman (Sloane, (23). Moreover, sexual education includes an individual understanding of physical, emotional & sexual development, the development of a positive concept of self, a respectful attitude towards other individual's rights, opinions, and behavior (6). Despite initiating conversations about sexuality & sexual behavior being challenging for parents of youth with disability, early sexuality education can foster independence and prevent victimization (Ballan, (24), through mitigating risks by empowering youth with disability and reinforcing their ability to seek support (25).

Andreassen et al (26) notes that excellent quality comprehensive sexuality education aligns with the United Nations Sustainable Development Goals, including goal 3 (good health and well-being), goal 4 (quality education), goal 5 (gender equality), as well as goal 16 (peace,

justice, and strong institutions). Furthermore, article 25 of the UNCRPD also acknowledges that people with disability should be provided with the same range, quality and standard free or affordable health care & programmes as provided to other persons, including in sexual and reproductive health and population-based public health programme (UN, 27). This provision assures people with disability access to health services including sexuality education without discrimination.

#### CHALLENGES FACED BY PARENT/GUARDIANS PROVIDING COMPREHENSIVE SEX EDUCATION TO CHILDREN LIVING WITH DISABILITY

**Parents' anxiety & fear:** majority of parents of youth with disability do not know how to deal with the problems, anxiety, and education regarding their child's sexual development (10) & (29). According to Gürol et al (29) study, it was reported that the parents expressed their fear and stated they believe school should educate their children on sexual health. They shift responsibility to schools whilst not setting boundaries or even passing on basic knowledge concerning sexual development (Hanass-Hancock et al, (30). Unfortunately, teachers are reluctant to provide school-based sex education due to lack of training, skills, preparation, knowledge, and confidence in delivering sexuality education (Maszarry et al, (31); Ram et al, (32). A study conducted in Turkey by Gürol et al (29) additionally stated that several parents have anxiety that if their children are sexually trained, they will have curiosity and wrong experiences. Moreover, Hanass-Hancock et al(30) reported that there is also a home environment challenge that is allied with grandparents who raise youth with disability, as they are perceived as soft, not informative with sexual information and do not set boundaries or enforce discipline on the youth. Subsequently, this role's parental anxiety may lead to parents avoiding sexuality (Kammes et al, (33).

Furthermore, Eyres et al (34) indicated that the parents fear of not knowing what, or how to teach concepts often cause them to provide limited or even denying sexuality education to their children. The fear & anxiety about how to approach and sexuality for youth play strong roles in the lives of the parents and professionals, and this not only prevents youth from receiving appropriate sexual education but also results in reproducing the associations between disability & asexuality of youth with disability within the society (East & Orchard, (35). Walker (36) and (37) notes that mothers are regarded as a major caregiver and health educators in the homes; fathers seem less involved in sexuality cases. Moreover, Queirós et al (38) argues that parents find it problematic to insert the theme of sexuality among the issues

discussed with children, as they are afraid and believe when talking or showing condoms could encourage the children to have sex, hence they do not establish a healthy dialogue or may take stricter measures with deliberate attempts to control and restrict youth sexual behaviors.

**Content & Timing:** Distinctively, developmental appropriateness of discussion, appropriate topics and anticipation are challenging (Ballard et al, (39). Parents avoid lengthy discussions to prevent misunderstandings and fear that the conversation would lead to exploration (Kamaludin et al, (40). Albeit parents may desire to talk to their children regarding sexuality, they are not sure of the timing of the education they should provide for the developmentally precise language or approach to use with their child as they do not want to overwhelm them, terrify them or have them come up with thoughts they did not have (39).

**Parents' paucity of knowledge:** In Kamaludin et al (40) study, all parents with low-to-moderate level of education expressed that they lack knowledge or skills in conveying sex education to their children, which inhibits their ability to effectively fulfill their role as principal sex educators. It was also indicated in the above-mentioned study that the parents were not previously exposed to adequate sex education in their life, rendering them inept to effectively educate their children. In the study the parents also acknowledged that the information they gave to their children was undeveloped and not detailed. Additionally, parent's sexual knowledge and attitudes regarding sex education are inseparable from their educational background (Jin, (41); Shin et al, (42). Furthermore, Lukolo& Dyk (43), mentioned that uneducated parents are unable to provide quality and adequate sexuality information due to their lack of knowledge about sexuality and that they grew up in an environment where such a topic was never discussed.

Similarly, in Kamaludin et al (40) findings discovered that the parents' level of sexual knowledge and attitudes regarding sex education are intricately linked to their educational level i.e., the greater academic level of a parent, the greater the extent of sexual knowledge and the more satisfactory the attitudes towards providing sex education to their children. Additionally, the parents do not know how to act upon the manifestations of sexuality of their children and feel unprepared to meet their demands & curiosity as they feel intellectually and emotionally unable to guide, lead, direct and monitor this stage of life (38); Walker, (36). Likewise, Othman et al (44) points out that many parents including those in Middle Eastern

countries may feel uninformed, unprepared, or embarrassed at the thought of engaging in parent-child sexuality communication (PCSC) with their children.

**Communication barrier:** Sex education is traditionally uncomfortable (Eyres et al, (34), hence why parents do not instigate conversations about the subject (Schaafsma et al, 2014(14). Consequently, when sex is taught, it is usually taught reactively in response to problems, rather than to preclude problems and proactively support youth with disability (Abbott & Burns, (45); as cited in Schaafsma et al, (14). The challenge of communicating clearly with the children was indicated as central by parents, noting the fear that they did not want to communicate unintended information about sexuality related topics (34). A common shared concern by parents was that they sometimes did not understand what their children uttered due to a variety of communication challenges including being non-verbal (Eyres et al, (34). This lack of communication can therefore result in negative implications for youth such as lower self-esteem, sexual identity confusion and doubt regarding their status as a sexual being (East & Orchard, 2013(35).

#### DISABILITY & SEXUALITY CONTENT WITHIN SOCIAL WORK EDUCATION

According to Dodd & Tolman (45) sexuality is not a veiled dimension within social work as they are frequently engaged with aspects of sexuality across all practice domains, and some of the most underlying & recurrent concerns of social workers include sexual abuse, sexual violence, commercial sex work, gender identity, troubled sexual & romantic relationships. On the contrary, Josefsson et al (46) points out that social work education has included minimum attention to disability, sexuality, and the intersection of disability & sexuality. In validation of the above statement made by Josefsson et al, Ballan (47) articulates that social workers provide vital services and adequate information about people with disability, however undergraduate and graduate curricula established to prepare social work students to meet the needs of clients with disabilities appear limited. For instance, in accordance with Dunn et al (48), only 17% of master's in social work (MSW) programs offered an elective addressing disability issues. Additionally, Wills et al(49); as cited in Ballan, (47) found that only 3 of the 27 Canadian schools of Social Work offered courses pertaining to disability issues. Similarly, in Botswana the social work education emphasizes on classifying people with disability as a marginalized group, as well as on disability social welfare service i.e., the Disability

Economic Empowerment Programme, nonetheless issues pertaining to their sexuality and academic electives offered are inadequate.

Although social work is deeply ingrained in social justice i.e., a critical strategy in their effort to improve human rights and social justice in disassembling systems of oppressions which contribute to the marginalization, though social work advocacy has not been prominent in disability rights, particularly around sexuality (Turner & Crane, (50). In accordance with Ballan (47), the study gave an instance that the lack of sexually explicit materials in Braille excludes individuals who are blind from this aspect of sexuality; hence it is not the absence of vision that creates the disability or barrier to participation but rather the absence of resources or materials. Additionally, Lee & Fenge (51) also urge that the sexual well-being of people with disabilities is a scarcely researched area of social work practice.

Social workers play a vital role like doctors in determining what sexual behavior is considered 'normal' (Sloane, (23). Medical educators as well as social workers are reluctant in dealing with and discussing sexual pleasure for people with disability, as they are uncomfortable, lack skills & knowledge as reasons they do not engage in conversations about sexuality with their clients (47)&(23). However, clients expect social workers to understand issues of intimacy and sexuality to provide guidance in these areas (Ballan, (47). The lack of attention to issues of sexuality in social work education, research and literature therefore creates a silence that itself contributes to a particular social construction of sexuality, hence creating barriers towards clients (Dodd & Tolman, (45) & lead to their decreased health (Josefsson et al, 46). Vaughn et al (52) articulate that disabled people actively seek professional aid to address sex-related concerns, and disabled individuals who identify as LGBTQIA+ may experience double jeopardy as they are integrated within two marginalized groups.

Lee & Fenge (51) consequently encourages that social workers comprehend the nuanced elements affecting identity, including the intersection of disability, sexuality, ethnicity & gender, as these will impact sexual wellbeing. Additionally, Turner & Crane (50) urges social worker educators dedicated to teaching practice based in cultural humility, must incorporate sexuality & disability into curriculum; challenge social work students to critically audit and explore their beliefs, values, myths, and ethics pertaining to sexuality & disability.

## RESEARCH METHODOLOGY

This is a cross-sectional qualitative exploratory study. Research designs are vital as they make the smooth navigation of various research procedures (Akhtar, (53). The study explored the parents' perspectives on comprehensive sex education for children with disability, the consequences, as well as the approaches used (Salkind,(54) & Neuman, (55). This study provides in-depth details of the perspectives of parents as the key educators of children, the challenges they encountered when providing comprehensive sex education to children with disability, and how they dealt with the situations and the challenges faced. Furthermore, I considered the feelings and concerns of each parent and drew conclusions based on what they said. The interviews were conducted at the participants' home following the purposive/sampling design (Salkind, (56).

#### DATA COLLECTION PROCEDURES OBSERVATION

The researcher observed whether the non-verbal cues contradict what the participants conveyed (Mulhall, (57). Ciesielska et al (58), argue that observation must be carried out systematically, with a focus on specific research questions. Similarly, this study was carried out following a detailed interview guide. The interviews were recorded with the consent of the participant, and an interview guide (see appendix 1) was also utilized to keep the research interview focused. As questions were asked, vital points were handwritten with the backup of audio recordings.

This study utilized a thematic analysis by Victoria Braun and Virginia Clarke. Thematic analysis is a method for identifying, analyzing, and reporting patterns within data (Braun & Clarke, (59). Additionally, Braun & Clarke thematic analysis provided an outline guide through six phases d as follows:

##### Phases of Thematic Analysis

###### *Phase 1: Familiarizing yourself with data*

The researcher collected data and familiarized with the content of the data in-depth by transcribing, reading, and re-reading data, and noting down vital points.

###### *Phase 2: Generating initial codes*

In this phase, the researcher coded interesting data in a systematic way across the entire data set.

### *Phase 3: Searching for themes*

This phase involved researchers coding data collected into potential themes and gathering all relevant data to each potential theme.

### *Phase 4: Reviewing of themes*

After formulating potential themes, they were then refined to ensure they are simple and clear. According to Braun & Clarke (59) some themes are categorized into separate themes while other themes are merged. At the end of this phase, the researcher will know the various themes to be utilized.

### *Phase 5: Defining & naming themes*

The themes were defined and further refined. Additionally, the essence and aspect of what each theme was about was captured.

### *Phase 6: Producing the report*

This ensured that write-up is logical, clear, and critical of the objectives. To produce a scholarly report analysis in this stage, the data analysis must be elaborative and engaging enough to persuade the reader that the data is reliable.

## **SAMPLING**

This study used non-probability sampling; it is a sampling technique in which the chance or probability of each unit to be selected is unknown or not confirmed by Rahi, (60). Additionally, Ayman (61) argues that the sampling technique is based subjective judgment and utilizes convenient selection of units from the population. Subsequently, this sampling section articulated the study site, units of analysis, study population, sampling technique and the sample size.

## **STUDY SITE**

Serowe is a steadily developing village; hence this study is trying to understand the attitudes, perceptions of parents and understand the challenges they face pertaining to disability & sexuality. Consequently, this research was conducted in the Central Region of Botswana in Serowe Village.

## UNIT OF ANALYSIS

The element of study of this research was the parents or guardians of children with disabilities.

## STUDY POPULATION

As the study requires a small sample size, the probable study population consisted of 20 parents/guardians of children with disabilities.

### List : 1 INCLUSION/ EXCLUSION CRITERIA

INCLUSION CRITERIA	EXCLUSION CRITERIA
<ul style="list-style-type: none"><li>-Parents/ Guardians of youth with disability</li><li>-Parents/ Guardians of youth aged 15-25 years</li><li>-Parents willing to consent</li></ul>	<ul style="list-style-type: none"><li>-Parents/ Guardians of youth without disability</li><li>-Parents/ Guardians of youth aged 0-14 years</li><li>-Parents unwilling to consent</li></ul>

## SAMPLING TECHNIQUE(S)

Purposive sampling: It was used to identify and select the information -rich cases for the most proper utilization of available resources (Etikan et al, (62). It is a form of non-probability sampling that enables the identification of characteristics of a population of interest to help answer the research questions (Etikan& Bala, (63). Likewise, this study intended to select participants that were knowledgeable about the phenomenon of interest, which in this case were the parents/guardians of youth with disability.

## SAMPLE SIZE

20 willing participants made up the sample size, which represented 10% of the 200 anticipated study populations.

## **PILOT STUDY**

To test the instrument (interview guide) and ensure the questions were flowing/ not repeating, three (3) participants from Thabala village were interviewed.

## **LIMITATIONS OF THE STUDY**

- Most of the parents/guardians that were available in Serowe village were children below (6-13 years) or above (+30 years) the target group, which was 15-25 years.
- Due to a shortage of participants in Serowe, this resulted in the researcher interviewing parents/guardians in the neighboring village (Paje).
- Some participants could not make it to the interview appointments due to work, funerals, and doctor appointments.

## **ETHICAL CONSIDERATIONS**

These research principles aim to assist researchers to coordinate their actions or activities and to establish participants' trust (Gajjar, (64). Three ethical principles that constituted the foundation for ethics in research were:

1. **The Principle of Beneficence:** Research must not cause harm to the participants and to people in general. Research should also make a positive contribution towards the welfare of people.
2. **Principle of respect for individuals (Autonomy):** Research must protect the rights and dignity of participants.
3. **Principle of Justice:** The benefits and risks of research should be distributed among people.

The three core principles were utilized by:

**Permission to conduct the study:** Before it was conducted, permission was sought from UB IRB and the Ministry/Government Department responsible. Permit forms were requested from the UB IRB Office.

**Procedure and Duration:** Participants were told of the interview's duration.

**Disclosure:** Participants were also informed fully about the research's nature and purpose and how information was to be collected.

***Voluntary participation:*** Participant's consent to participate was voluntary, and free of any coercion.

***Confidentiality:*** Participants were assured that all information and recordings provided by participants or obtained directly, or indirectly on/about participants were to be kept confidential.

Deception: Participants were never deliberately misled to get certain information.

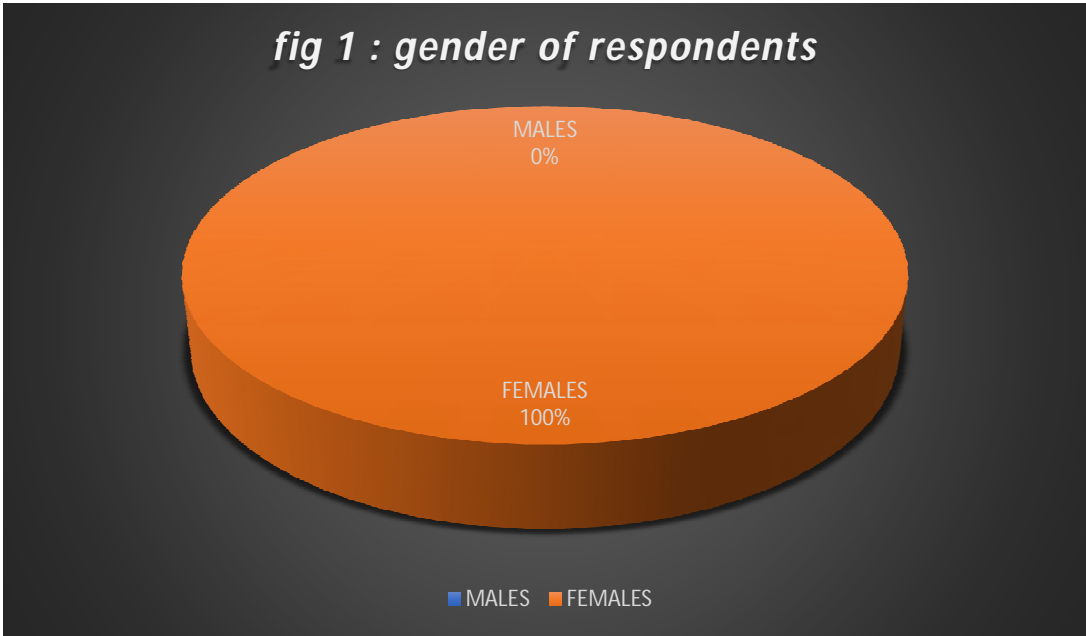
***Withdrawal from investigation:*** Right from the beginning, participants were informed that they have the right to withdraw from the research at any time irrespective of whether payment of incentives has been granted.

***Protection of participants:*** Participants were protected from physical and mental harm during the investigation. There are diverse types of harm; psychological, financial, emotional, physical etc. The participant was to be referred to a social worker for assistance with immediate effect.

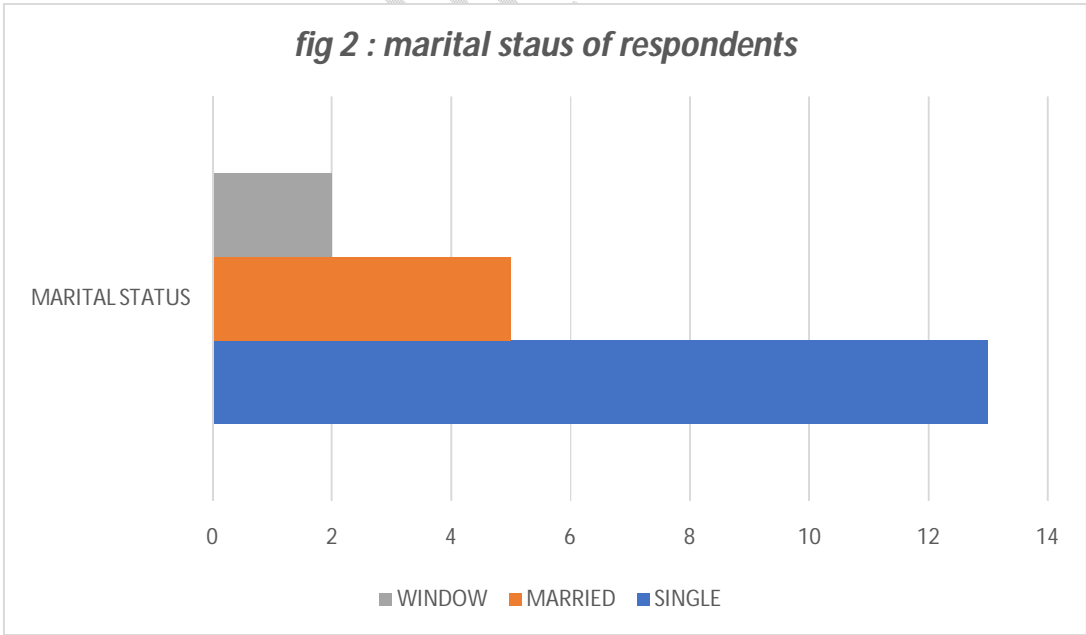
***Dissemination of the findings:*** After completion of the study, copies of the report were deposited to relevant stakeholders including the University of Botswana library deposits. If funds permit, the findings will be disseminated through a seminar or workshop.

## **FINDINGS**

### **CHARACTERISTICS OF PARTICIPANTS**

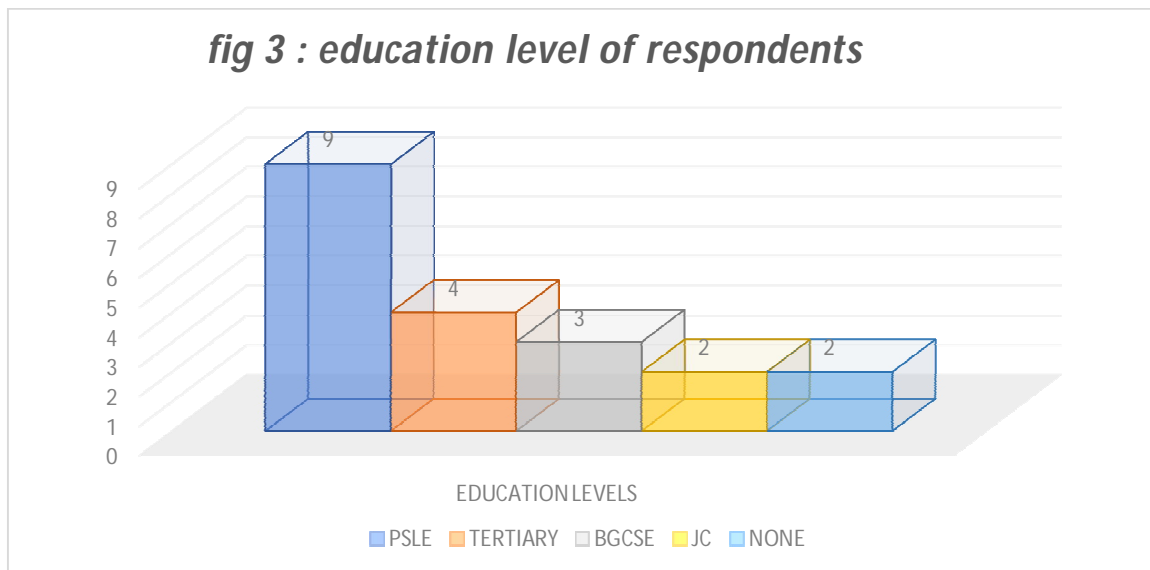


The figure above displays that all the participants interviewed in this study was females. These are mostly single parents to youth with disability, as well as women considered to be the health educators at homes (Walker, (36). Historically, gender norms have designated women as the primary caregivers for their families, because they are viewed as more compassionate and empathetic compared to men, leading them to promote and maintain the health of their loved ones, thus may be the reason for having all the participants as females.



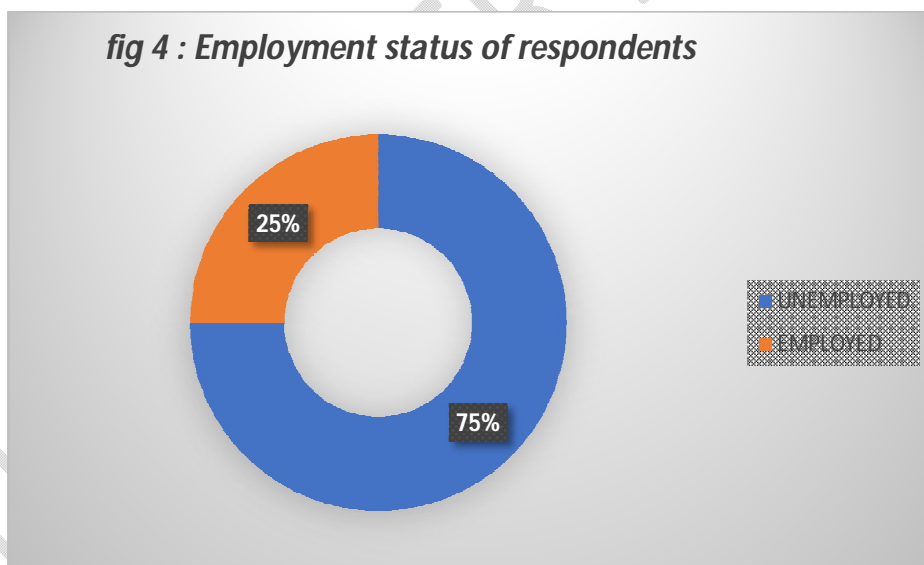
In figure above, 13 (65%) of participants were single, 5 (25%) were Married females, and 2 (10%) comprised widows.

**fig 3 : education level of respondents**



Out of the 20 participants interviewed, 9 (45%) reported having primary education and 2 (10%) have pursued junior level education. Moreover, BGCSE education level was completed by 3 participants (15%), and only 4 participants (20%) had tertiary level education. Only 2 participants (10%) had no formal education.

**fig 4 : Employment status of respondents**



The figure shows that 15 participants (75%) were unemployed; they reported living on temporary part-time jobs. Those employed were 5 participants (25%), they started to be secretaries, teachers, cleaners, lab assistants as well as nurses.

#### THE IMPORTANCE OF COMPREHENSIVE SEX EDUCATION FOR YOUTH WITH DISABILITY

- Prone to sexual abuse

The participants mentioned that in this modern era, youth with disabilities are vulnerable, susceptible to sexual abuse and exploitation. It is the parent's "responsibility" to provide sex education; a sister of a 23-year-old male with Down syndrome, said that *"It is the parents' responsibility to educate their children, before there is any external influence"* (R11). The participants deem it vital for parents to educate their children, 6 of 20 participants believe that parents/ guardians should consider the youth's mental development before sharing sex related information with them.

In addition, another participant reported that *"it is important to educate them because there are some men out there that are heartless enough to manipulate children with disabilities with gifts to sexually exploit them"* (R1). Parents, however, should be mindful that both men and women do take advantage of youth with disabilities, so we cannot only blame men for sexual exploitation.

#### □ **Protection measures**

Most participants reported that it is vital to provide comprehensive sex education to equip the youth with disability with protection measures to fend for themselves in the absence of their guardian/parent in case they are sexually exploited. A single mother of a 17-year-old boy with Down syndrome stated that;

*"Yes, it is important. Our children are prone to sexual abuse; we never know whom our children are safe with. We are always vigilant and should educate them on how to protect themselves and be aware of such incidents."* (R9)

Contrary to views about sex education for the youth with disability, a handful of participants pointed out that it is not important to *"encourage"* youth with disability regarding sex related matters. An elderly widow (grandmother) of a 16-year-old boy with intellectual disability commented that;

*"The children are unpredictable; they might act contrary to what they are taught. They might end up contracting STD's/STI's which in turn becomes burdensome on their parents."* (R2)

#### □ **Sexual relations**

*"Parents should guide them on what's appropriate and inappropriate conduct. These children too are humans, they have feelings. They have sexual desires as those without disability."* (R3), said a grandmother of an 18-year-old girl with intellectual disability. This implies that sexual desire is an inherent characteristic of human nature, and that it is not limited to certain individuals or groups based on their traits or affiliations.

### **CHALLENGES/ CONCERNS ENCOUNTERED BY PARENTS/GUARDIANS WHEN PROVIDING COMPREHENSIVE SEX EDUCATION**

Majority (14 participants, 70%) reported encountering challenges when sharing sex related information with their children with disabilities. However, 6 participants (30%) had not encountered such problems. Some of the challenges encountered are:

#### □ **Communication barrier**

Among the participants, a lady in her early thirties who is a proxy to her brother mentioned that children with disabilities like any individual are sexually exploited. Her brother's disability (intellectual disability & Down syndrome) makes it difficult to educate him on sex matters because of his mental development, as well as his speech impairment. Certain disabilities may hinder an individual's capacity to communicate effectively, thereby creating challenges in comprehending, conveying, and interpreting their non-verbal cues, which influences their interpersonal relationships.

#### □ **Youth distorting parents' words/ teachings**

A mother of a male youth with mild cerebral palsy commented that *'I fear that he will twist my words & do something and say I am the one who taught him to do those things. Hence, the need for parent-teacher collaboration approaches to identify the best ways to educate children to avoid providing contradictory messages'* (R7). The mother appeared worried about the child distorting her words and using them against her. This is a complex situation to handle, but crucial to safeguard the child's interests.

#### □ **Youth reciting teachings in public**

A single mother whose child is a teenage girl with cerebral palsy revealed that the child is mentally undeveloped with a low comprehension level. She used the term *'mongolo'* to show that the child will not grasp anything and unable to differentiate between what is right or wrong, thus if she is given information, *'she might recite what was said publicly, which is inappropriate'* (R4). Nevertheless, this term *'mongolo'* is considered offensive when referring to an individual with a disability or towards people who are perceived to be mentally challenged or slow-witted. This label focuses on the disability rather than the person's unique qualities, which diminishes identity. Consequently, guardians and individuals should use considerate and comprehensive language that acknowledges the worth and dignity of all individuals, irrespective of their abilities or disabilities.

In addition, another mother of a 16-years-old boy with Down syndrome seemed concerned with her child's mental capacity when it comes to sex education. She commented that *'she prefers talking to him, but his mental capability does not match his age. For her to show him contraceptives, she will have to show him how to use them. He sometimes runs around naked. So, it is possible for him to put on the condom and run outside to show people, which are unacceptable'* (R17).

#### □ **External influences (peers, media)**

Since young people with disabilities are often socially excluded, they, like all young people, crave acceptance and recognition. They may feel compelled to conform to societal norms to belong and feel included. A teacher whose child has a learning disability confirmed that *"In this modern era, children are easily manipulated, influenced by their peers and social media. We educate them, and they stray from our teachings"* (R6). Due to lack of guidance on decision-making and sex education, they are more susceptible to misinformation by their peers and the social media.

#### □ Low level of comprehension

A person with disability has distinctive qualities, capabilities, and difficulties based on their specific disability and individual circumstances. A nurse commented that *'It depends on the child's level of maturity. For instance, based on my child's age she is slow to understand, hence I cannot assert the appropriate age for provision of sex education. Sometimes she behaves like a 9-year-old' (R9)*. This asserts that certain disabilities impede youth the capacity to comprehend information, resulting in a slower comprehension rate and a struggle to keep up with their peers and comprehend at the same level.

### DISCUSSION

The findings revealed that youth with disabilities are at risk of sexual exploitation due to a lack of sex education. Participants suggested that providing sexual education to young people would make them more aware of potential dangers and reduce the likelihood of sexual abuse. These findings are consistent with Hanass-Hancock et al (30) research, which showed that the absence of sexual and reproductive health and rights services, including comprehensive sexuality education, increases the vulnerability of young people with disabilities to HIV and sexual violence.

Most parents/guardians emphasized the importance of sex education to youth with disabilities. They believed that such education would be beneficial to their children, both in terms of teaching them how to protect themselves and being cautious when their caregivers are absent, as they might be at risk of sexual abuse. However, they also noted that these young people's mental development should be considered before providing such education. Furthermore, few participants disagreed with the notion that sex education is necessary, because they believed that it could encourage inappropriate behavior, such as running around naked in public. This perspective is consistent with that of Queiros et al (37), who found that parents are hesitant to discuss the use of contraceptives with their children, because they fear that it might lead to increased sexual activity. However, Gürol et al (2014)(28) discovered that mothers of children who engage in such behavior (running around naked) advocate for sex education, to prevent and reduce these fears.

Despite the diverse perceptions on the necessity of sex education for youth with disabilities, parents often do not know how to begin a discussion on the topic. This is due to the (parent/guardians) strict cultural upbringing and a lack of information on sex-related issues, which are traditionally considered taboo, embarrassing, or inappropriate. **These findings are consistent with several studies (Tsuda et al, 65; Ariadni, Prabandari& Sumarni, (36); Beyers, (66); Michielsen & Brockschmidt, (67) that attest that sexual education is widely influenced by cultures, religions, and diverse customs in various communities. Accordingly, the general existence of sexuality education as taboo follows intergenerational norms of respect, which are often subverted when convenient for the older person who sanctions such conventions (Gbewonyo, (13)).**As a result, parents rely on school-based sex educational programmes. Parents may perceive school-based sex education programs as a reliable source of information, to equip their children with the essential knowledge and competencies. This is consistent with Hanass-Hancock et al (30), who found that sex education poses challenges because of conservative views and values. **Moghadam & Ganji (68), point out that informing**

the family about the psychosocial development of children and empowering them to establish a good and desirable relationship will lead to a family-centered approach to the development & development of sexual behaviors, issues, and sexual problems of the child. This will provide the youth with the opportunity to make informed decisions regarding their sexuality as their parents will be actively guiding and supporting them in the choices they make. Additionally, parental reluctance to educate youth with disabilities might be associated with the lack of knowledge on how to address sensitive topics that conflict with cultural values. Furthermore, the interplay of cultural upbringing, limited awareness, and the probable conflict between cultural beliefs and the necessity for inclusive sexual education can pose significant barriers for parents in initiating and competently addressing this vital aspect of their child's growth.

### **Challenges/ concerns encountered by parents/guardians when providing sex education to youth with disability**

The participants face various challenges/ concerns when providing sex education to their children with disabilities. These encompassed language barriers, low cognitive comprehension level among youth, public recitation of teachings by youth, external influences, and misinterpretation of teachings by youth. However, few of them did not encounter any hindrances. For example, youths with intellectual disability and Down syndrome, cognitive development and speech impairment posed challenges to sex communication and education. This challenge is consistent with the studies by Bray & Grad (69), Tuffrey-Wijne&McEnhill (70) as they point out that people with intellectual disabilities struggle or experience difficulties with communication or verbal skills and lack of comprehension. Although people with intellectual disabilities have communication difficulties or lack expressive communication skills, they are more likely to understand their expressive abilities than would be apparent (Chew et al, (71). This therefore denotes that will or may have difficulties communicating effectively with their children on reproductive or sexual health; thus the need to consider tailoring concepts and explanations inclusive of age-appropriate and multi-disciplinary approach to quality life in order to meet of persons with disabilities (Lawthers et al, (72); Lindsay & Edwards, (73); Chew et al, (71).

Sexuality is a personal and sensitive issue and discussing it in public may elicit adverse reactions. Reciting information in public and distorting parents' information are among the challenges/ concerns identified by this study. Youth with disabilities may not fully grasp societal norms regarding sexual behavior and may struggle to differentiate between acceptable and unacceptable conduct in public. Consequently, this might expose them to becoming targets of harassment and victimization. The study by Menon & Sivakami (74) also attested to the above notion as parents feared that educating their children could lead to habit formation such as self-stimulation in public or seeking someone to fulfill their sexual urges, which may get them in trouble with the law and the society.

Additionally, it was discovered that all the participants were women, who mostly are of single parent status, and the primary caregivers for health matters at home. This finding replicates the results of multiple studies by (Ballard & Morris, (75); Guzman et al., (76); Walker, (77); as cited in Ballard & Gross (78). Their research revealed that mothers take greater responsibility for providing sexual education within the family. Ballard & Gross (78) stated that it is crucial to promote equal participation of both fathers and mothers in this

process. Furthermore, the parents in the afore-mentioned study expressed apprehensions about gender in relation to effective sexual communication. It also emphasized that it is essential to support and encourage same-gender communication (fathers talking to sons), and that effective opposite-gender communication (mothers talking to sons or fathers talking to daughters) should not be disregarded as a crucial component of sexuality education, and the inclusion of opposite-gender communication may be particularly important for single-parent families and LGBTQ+ families.

There is limited research on homosexuality for people with disabilities and people's attitudes towards the topic are typically unfavorable (Schaafsma et al, 2014(14). The same study also notes that LGBTQ+ individuals with disabilities feel lonely, isolated, and facing negative reactions regarding their sexual orientation.

## **CONCLUSION**

In summary, this study accentuates the significance of imparting sexual education to youth who have disabilities. The lack of such education renders them vulnerable to sexual exploitation and mistreatment. Nevertheless, delivering this education can pose obstacles due to communication barriers, limited comprehension abilities, and traditional cultural norms. Furthermore, this study underlines the significance of involving both parents, particularly fathers, in the teaching process. It also advocates for the creation of a clear and age-appropriate curriculum for sexual education that can be easily comprehended by people with disabilities. Ultimately, providing sexual education to young individuals with disabilities is vital for safeguarding their safety and welfare.

## REFERENCES

1. Wos, K., Kamecka-Antczak, C., & Szafranski, M. (2020). In search of solutions regarding the sex education of people with intellectual disabilities in Poland- participatory action research. *European Journal of Special Needs Education*, 6(4), 1–14.
2. Campbell, M., Löfgren-Mårtenson, C., & Martino, A. S. (2020). Crippling sex education. *Sex Education*, 20(4), 361-365.
3. Anderson, S. (2015). Sex education programs focused on “protection” and “prevention” with little attention given to supporting people to develop healthy, positive sexual relationships. *Research and Practice in Intellectual and Developmental Disabilities*, 2(1), 98-100.
4. Azzopardi-Lane, C. (2022). “It's not easy to change the mentality”: Challenges to sex education delivery for persons with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 35(4), 1001-1008.
5. United Nations. (2021). Youth with disabilities. Retrieved from [Youth with disabilities | United Nations Enable](#).
6. Guven, S., & İŞLER DALGIÇ, A. Y. Ş. E. G. Ü. L. (2015). Sex education and its importance in children with intellectual disabilities. *Journal of Psychiatric Nursing*, 6(3).
7. Neufeld, J. A., Klingbeil, F., Bryen, D. N., Silverman, B., & Thomas, A. (2002). Adolescent sexuality and disability. *Physical Medicine and Rehabilitation Clinics*, 13(4), 857-873.
8. United Nations Children’s Fund. (2021). Retrieved from [Nearly 240 million children with disabilities around the world, UNICEF’s most comprehensive statistical analysis finds](#).
9. Bawden, A. (2022). Almost a third of disabled children & teenagers face abuse. The Guardian News Website of the year. International edition.
10. Treacy, A. C., Taylor, S. S., & Abernathy, T. V. (2018). Sexual health education for individuals with disabilities: A call to action. *American Journal of Sexuality Education*, 13(1), 65-93.
11. UNICEF (2013). [Children and Young People with Disabilities: Fact Sheet](#). [http://www.unicef.org/disabilities/files/Factsheet\\_A5\\_\\_Web\\_NEW.pdf](http://www.unicef.org/disabilities/files/Factsheet_A5__Web_NEW.pdf)

12. Kassa, T. A., Luck, T., Bekele, A., & Riedel-Heller, S. G. (2016). Sexual and reproductive health of young people with disability in Ethiopia: a study on knowledge, attitude, and practice: a cross-sectional study. *Globalization and health, 12*(1), 1-11.
13. Gbewonyo, Y. A. (2017). *Parents and Special Educators' Perspectives on the Sexuality Educational Needs of Learners with Intellectual Developmental Disabilities in Ghanaian Special Schools* (master's thesis, Queen's University (Canada)).
14. Schaafsma, D., Kok, G., Stoffelen, J. M., Van Doorn, P., & Curfs, L. M. (2014). Identifying the important factors associated with teaching sex education to people with intellectual disability: A cross-sectional survey among paid care staff. *Journal of Intellectual and Developmental Disability, 39*(2), 157-166.
15. Munthali, A., Mvula, P., & Ali, S. (2004). Effective HIV/AIDS and reproductive health information to people with disabilities.
16. de Reus, L., Hanass-Hancock, J., Henken, S., & van Brakel, W. (2015). Challenges in providing HIV and sexuality education to learners with disabilities in South Africa: the voice of educators. *Sex Education, 15*(4), 333-347.
17. van Pletzen, E., Kabaso, B., & Lorenzo, T. (2021). Community-based workers' capacity to develop inclusive livelihoods for youth with disabilities in Botswana. *African Journal of Disability, 10*.
18. Mukhopadhyay, S., & Moswela, E. (2020). Disability rights in Botswana: Perspectives of individuals with disabilities. *Journal of Disability Policy Studies, 31*(1), 46-56.
19. Stein, S., Kohut, T., & Dillenburg, K. (2018). The importance of sexuality education for children with and without intellectual disabilities: What parents think. *Sexuality and Disability, 36*(2), 141-148.
20. Holland-Hall, C., & Quint, E. H. (2017). Sexuality and disability in adolescents. *Pediatric Clinics, 64*(2), 435-449.
21. SIECUS (2014). Fact sheets questions and answers: Sexuality education. Retrieved from [Issues and Answers: Fact Sheet on Sexuality Education \(thebody.com\)](https://www.thebody.com/resources/Issues_and_Answers_Fact_Sheet_on_Sexuality_Education)
22. Tissot, C. (2009). Establishing sexual identity: Case studies of learners with autism and learning difficulties. *Autism, 13*(6), 551-566.
23. Sloane, H. M. (2014). Tales of a reluctant sex radical: Barriers to teaching the importance of pleasure for wellbeing. *Sexuality and Disability, 32*, 453-467.

24. Ballan, M. S. (2012). Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 42(5), 676-684.
25. McDaniels, B., & Fleming, A. R. (2016). Sexual Education and Intellectual Disability: Time to Address the Challenge. *Sexuality and Disability*, 34(2), 215-225. <https://doi.org/10.1007/s11195-016-9427-y>.
26. Andreassen, K., Quain, J., & Castell, E. (2024). Stop leaving people with disability behind: Reviewing comprehensive sexuality education for people with disability. *Health Education Journal*, 00178969241269656.
27. United Nations. (2006). United Nations Convention on the Rights of Persons with Disabilities. Retrieved from [Convention on the Rights of Persons with Disabilities](#).
28. Gürol, A., Polat, S., & Oran, T. (2014). Views of mothers having children with intellectual disability regarding sexual education: A qualitative study. *Sexuality and Disability*, 32(2), 123-133.
29. Hanass-Hancock, J., Nene, S., Johns, R., & Chappell, P. (2018). The impact of contextual factors on comprehensive sexuality education for learners with intellectual disabilities in South Africa. *Sexuality and Disability*, 36(2), 123-140.
30. Maszarry, S. A., Anal, A., & Ibrahim, R. (2021). Delivery of Sexuality Education to Students with Intellectual Disabilities in Secondary Schools: Educators' Perspective. *International Journal of Academic Research in Progressive Education and Development*, 10(4), 84-93.
31. Ram, S., Andajani, S., & Mohammadnezhad, M. (2020). Parent's perception regarding the delivery of sexual and reproductive health (SRH) education in secondary schools in Fiji: A qualitative study. *Journal of environmental and public health*, 2020.
32. Kammes, R. R., Douglas, S. N., Maas, M. K., & Black, R. S. (2020). Parental support for sexuality education and expression among adults with an intellectual disability. *Sexuality and Disability*, 38(4), 669-686.
33. Eyres M. R., Hunter C, W., Happel-Parkins A., Williamson L. R., & Casey L B. (2022) Important Conversations: Exploring Parental Experiences in Providing Sexuality Education for Their Children with Intellectual Disabilities, *American Journal of Sexuality Education*.
34. East, L. J., & Orchard, T. R. (2014). Somebody else's job: experiences of sex education among health professionals, parents, and adolescents with physical disabilities in Southwestern Ontario. *Sexuality and Disability*, 32(3), 335-350.

35. Walker\*, J. (2004). Parents and sex education—looking beyond ‘the birds and the bees. *Sex education*, 4(3), 239-254.
36. Ariadni, D. K., Prabandari, Y. S., & Sumarni, D. W. (2017). The Parents’ Perception of Having Children with Intellectual Disabilities Provided with Sex Education. *Indonesian Nursing Journal of Education and Clinic (INJEC)*, 2(2), 164-169.
37. Queirós, P. D. S., Pires, L. M., Matos, M. A., Junqueira, A. L. N., Medeiros, M., & Souza, M. M. D. (2016). Conceptions of parents of adolescent students about the sexuality of their children.
38. Ballard, S. M., & Gross, K. H. (2009). Exploring parental perspectives on parent-child sexual communication. *American Journal of Sexuality Education*, 4(1), 40-57.
39. Kamaludin, N. N., Muhamad, R., Mat Yudin, Z., & Zakaria, R. (2022). “Providing Sex Education Is Challenging”: Malay Mothers’ Experience in Implementing Sex Education to Their Children with Intellectual Disabilities. *International Journal of Environmental Research and Public Health*, 19(12), 7249.
40. Jin, X. (2021). The characteristics and relationship of parental sexual knowledge and sex education attitude to young children.
41. Shin, H., Lee, J. M., & Min, J. Y. (2019). Sexual knowledge, sexual attitudes, and perceptions and actualities of sex education among elementary school parents. *Child Health Nursing Research*, 25(3), 312.
42. Lukolo, L. N., & van Dyk, A. (2015). Parents’ participation in the sexuality education of their children in rural Namibia: a situational analysis. *Global Journal of Health Science*, 7(1), 35.
43. Othman, A., Shaheen, A., Otoum, M., Aldiqs, M., Hamad, I., Dabobe, M., ... & Gausman, J. (2020). Parent–child communication about sexual and reproductive health: perspectives of Jordanian and Syrian parents. *Sexual and reproductive health matters*, 28(1), 1758444.
44. Abbott, D., & Burns, J. (2007). What’s love got to do with it? Experiences of lesbian, gay, and bisexual people with intellectual disabilities in the United Kingdom and views of the staff who support them. *Sexuality Research & Social Policy*, 4, 27-39.
45. Dodd, S. J., & Tolman, D. (2017). Reviving a positive discourse on sexuality within social work. *Social work*, 62(3), 227-234.
46. Josefsson, K. A, Rolander, B., & Bülow, P. (2019). Swedish social work students’ attitudes toward addressing sexual health issues in their future profession. *Sexuality and Disability*, 37(2), 161-173.

47. Ballan, M. S. (2008). Disability and sexuality within social work education in the USA and Canada: The social model of disability as a lens for practice. *Social Work Education, 27*(2), 194-202.
48. Dunn, P. A., Hanes, R., Hardie, S., & MacDonald, J. (2006). Creating disability inclusion within Canadian schools of social work. *Journal of Social Work in Disability & Rehabilitation, 5*(1), 1-19.
49. Wills G., & Members of the Persons with Disabilities Caucus. (1993). Workshop on persons with disabilities and social work education in Canada.
50. Turner, G. W., & Crane, B. (2016). Sexually silenced no more, adults with learning disabilities speak up: A call to action for social work to frame sexual voice as a social justice issue. *The British Journal of Social Work, bcw133*.
51. Lee, S., & Lee-Ann, F. (2016). Sexual well-being and physical disability. *The British Journal of Social Work, bcw107*.
52. Vaughn, M., McEntee, B., Schoen, B., & McGrady, M. (2015). Addressing Disability Stigma within the Lesbian Community. *Journal of Rehabilitation, 81*(4).
53. Akhtar, D. M. I. (2016). Research design. *Research Design (February 1, 2016)*
54. Salkind, N. J. (Ed.). (2010). *Encyclopedia of research design* (Vol. 1). sage.
55. Neuman, L. W. (2014). Social research methods: qualitative and quantitative approaches.
56. Mulhall, A. (2003). In the field: notes on observation in qualitative research. *Journal of advanced nursing, 41*(3), 306-313.
57. Ciesielska, M., Boström, K. W., & Öhlander, M. (2018). Observation methods. In *Qualitative methodologies in organization studies* (pp. 33-52). Palgrave Macmillan, Cham.
58. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77–101. <https://doi.org/10.1191/1478088706qp063oa>
59. Rahi, S. (2017). Research design and methods: A systematic review of research paradigms, sampling issues and instrument development. *International Journal of Economics & Management Sciences, 6*(2), 1-5.
60. Ayhan, H. Ö. (2011). Non-probability Sampling Survey Methods. *International encyclopedia of statistical science, 14*, 979-982.
61. Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American journal of theoretical and applied statistics, 5*(1), 1-4.

62. Etikan, I., & Bala, K. (2017). Sampling and sampling methods. *Biometrics & Biostatistics International Journal*, 5(6), 00149.
63. Gajjar, D. (2013). Ethical consideration in research. *Education*, 2(7), 8-15.
64. Tsuda, S., Hartini, S., Hapsari, E. D., & Takada, S. (2017). Sex education in children and adolescents with disabilities in Yogyakarta, Indonesia from a teachers' gender perspective. *Asia Pacific Journal of Public Health*, 29(4), 328-338.
65. Beyers, C. (2011). Sexuality education in South Africa: A sociocultural perspective. *Acta Academica*, 43(3), 192-209.
66. Michielsen, K., & Brockschmidt, L. (2021). Barriers to sexuality education for children and young people with disabilities in the WHO European region: a scoping review. *Sex Education*, 21(6), 674-692.
67. Moghadam, S. H., & Ganji, J. (2019). The role of parents in nurturing and sexuality education for children from Islamic and scientific perspective. *Journal of Nursing and Midwifery Sciences*, 6(3), 149-155.
68. Bray, A., & Grad, D. (2003). Effective communication for adults with an intellectual disability. *Wellington: Donald Beasley Institute*.
69. Tuffrey-Wijne, I., & McEnhill, L. (2008). Communication difficulties and intellectual disability in end-of-life care. *International journal of palliative nursing*, 14(4), 189-194.
70. Chew, K. L., Iacono, T., & Tracy, J. (2009). Overcoming communication barriers: Working with patients with intellectual disabilities. *Australian family physician*, 38(1/2), 10-14.
71. Lawthers, A. G., Pransky, G. S., Peterson, L. E., & Himmelstein, J. H. (2003). Rethinking quality in the context of persons with disability. *International Journal for Quality in Health Care*, 15(4), 287-299.
72. Lindsay, S., & Edwards, A. (2013). A systematic review of disability awareness interventions for children and youth. *Disability and rehabilitation*, 35(8), 623-646.
73. Menon, P., & Sivakami, M. (2019). Exploring parental perceptions and concerns about sexuality and reproductive health of their child with intellectual and developmental disability (IDD) in Mumbai. *Frontiers in Sociology*, 4, 58.
74. Ballard, S. M., & Morris, M. L. (1998). Sources of sexuality information for university students. *Journal of sex education and therapy*, 23(4), 278-287.

75. Guzmán, B. L., Schlehofer-Sutton, M. M., Villanueva, C. M., Stritto, M. E. D., Casad, B. J., & Feria, A. (2003). Let us talk about sex: How comfortable discussions about sex impact teen sexual behavior. *Journal of health communication*, 8(6), 583-598.
76. Walker, J. L. (2001). A qualitative study of parents' experiences of providing sex education for their children: The implications for health education. *Health Education Journal*, 60(2), 132-146.
77. Walker-Hirsch, L. (Ed.). (2007). *The facts of life--and more: sexuality and intimacy for people with intellectual disabilities*. Brookes Pub.
78. Ballard, S. M., & Gross, K. H. (2009). Exploring parental perspectives on parent-child sexual communication. *American Journal of Sexuality Education*, 4(1), 40-57.

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