

CHAPTER 2

SEXUAL AND REPRODUCTIVE EXPERIENCES OF YOUTH WITH DISABILITIES IN ZIMBABWE

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Summary

Over 120 million youth with disabilities around the world face challenges related to sexual and reproductive health (SRH) services, such as unwanted pregnancy, sexually transmitted infections, and forced abortions and sterilisations. The main causes are cultural, legal, political, and social practices that restrict their rights. Our study explored sexual expectations and experiences of youth with disabilities. We conducted a qualitative study of 20 youth with disabilities using focus group discussions and semi-structured interviews, and then applied a thematic analysis of the data. The findings reveal that youth with disabilities are discriminated against with regard to accessing SRH information. This early exclusion results in discriminatory treatment at other stages of their lives, such as the onset of sexual relationships and marriage. They may also indulge in risky sexual behaviours which expose them to sexually transmitted diseases. Conversely, engaging in relationships, marriage and parenthood brings positive results, especially to women with disabilities. Marrying a non-disabled partner is viewed by disabled men as countering social discrimination. Some of the experiences suggest that parenthood has potential for bringing new status and social capital to persons with disabilities. Our primary recommendations based on this research are that youth-focused SRH schemes need to be redesigned to serve the public health needs of youth with disabilities, a vulnerable population that remains excluded from programming; and girls and women with disabilities should be especially targeted within these redesigned SRH programmes.

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1 Introduction

More than 120 million youth worldwide live with disabilities.¹ The World Health Organisation defines disability as an umbrella term for impairments, activity limitations and participation restrictions. Much like other youth, youth with disabilities face numerous challenges relating to their sexual and reproductive health (SRH). These include sexual health issues, unwanted pregnancy, sexually transmitted infections, and forced abortions and sterilisations. The SRH of youth with disabilities, however, continues to be overlooked and ignored,² mainly because disability is viewed from a medical model that equates disability with illness³ and assumes that persons with disabilities do not have sexual desires⁴ or are hypersexual, and are incapable of participating in sexual acts.⁵ Such stereotypes regarding persons with disabilities create barriers for their equal access to the SRH services to which they are entitled by national constitutions, international laws, and, prominently, the Convention on the Rights of Persons with Disabilities (CRPD).⁶ Women with disabilities are more deeply affected by these negative attitudes, even in comparison to their male counterparts.⁷

Persons with disabilities face these challenges because discrimination against them starts at an early age, originating from their parents and schools. The important role of parents in sex education for their children has been demonstrated by many studies.⁸ However, research has also shown that parents of children with disabilities are particularly uncomfortable teaching them about sexual and reproductive issues because of their anxiety, fear and lack of preparation.⁹ Schools can likewise play a role in teaching SRH issues to learners with disabilities.

- 1 UNICEF 'Children and young people with disabilities fact sheet' (2013) A5 available at [https://www.unicef.org/disabilities/files/Factsheet_A5_Web_REVISIED\(1\).pdf](https://www.unicef.org/disabilities/files/Factsheet_A5_Web_REVISIED(1).pdf) (accessed 8 October 2020).
- 2 R Addlakha, J Price & S Heidari 'Disability and sexuality: Claiming sexual and reproductive rights' (2017) 25 *Reproductive Health Matters* 50.
- 3 C Ngwena 'Reproductive autonomy of women and girls under the Convention on the Rights of Persons With Disabilities' (2018) 140 *International Journal of Gynecology and Obstetrics* 128.
- 4 JA Haegele & S Hodge 'Disability discourse: Overview and critiques of the medical and social Models (2016) 68 *Quest* 193.
- 5 T Rugoho & F Maphosa 'Challenges faced by women with disabilities in accessing sexual and reproductive health in Zimbabwe: The case of Chitungwiza town' (2017) 6 *African Journal of Disability* 252.
- 6 C Peta, T Wengraf & J McKenzie 'Facilitating the voice of disabled women: The biographic narrative interpretive method (BNIM) in action' (2019) 4 *Journal of the Academy of Social Sciences* 515.
- 7 A Gartrell, K Baesel & C Becker "'We do not dare to love": Women with disabilities' sexual and reproductive health and rights in rural Cambodia' (2017) 25 *Reproductive Health Matters* 31.
- 8 J Gupta et al 'Disability status, intimate partner violence and perceived social support among married women in three districts of the Terai region of Nepal' (2018) 3 *BMJ Global Health* 3.
- 9 O Robinson 'Moving toward disability justice' (2017) 37 *Disability Studies Quarterly* 1.

Indeed, comprehensive sex education has been recommended for all schools in South Africa, the United States and many other countries.¹⁰ But many teachers are especially uncomfortable discussing sexual issues with their disabled students.¹¹ Even when teachers are willing to make an effort to include learners with disabilities, those youth are often excluded from public schools in low-income countries.¹² In Zimbabwe, for example, it is estimated that approximately 600 000 students with disabilities of school-going age are not attending school.¹³ These youth will be illiterate, miss any provided SRH education, and likely be unable to read the written SRH information that is distributed in their communities.¹⁴ In an effort to promote SRH for persons with disabilities, a human rights approach has been adopted internationally.

1.1 A human rights-based approach to sexual and reproductive health for persons with disabilities

Access to quality and affordable SRH services for persons with disabilities has featured prominently as a human rights issue since the beginning of the 21st century. The CRPD's adoption was a reaction to the exclusion of the rights of persons with disabilities within the broader human rights agenda.¹⁵ Referencing similar provisions in the Universal Declaration of Human Rights and other core human rights treaties,¹⁶ the CRPD explicitly and broadly recognises the equal SRH of persons with disabilities.¹⁷ It does so by challenging cultural, social, political and religious practices that may harm the rights of disabled persons, including those impacting marriage, family, parenthood and relationships.¹⁸ The right of persons with disabilities to the autonomy of their bodies is similarly recognised, including attendant rights to be married and have children.¹⁹

- 10 JA McKenzie 'Disabled people in rural South Africa talk about sexuality' (2013) 15 *Culture, Health & Sexuality* 372.
- 11 J Khubchandani et al 'Providing assistance to the victims of adolescent dating violence: A national assessment of school nurses' Practices' (2013) 83 *Journal of School Health* 127.
- 12 D Schaafsma et al 'People with intellectual disabilities talk about sexuality: implications for the development of sex education' (2017) 35 *Sexuality and Disability* 21.
- 13 H Kuper et al 'The impact of disability on the lives of children: Cross-sectional data including 8,900 children with disabilities and 898,834 children without disabilities across 30 countries' (2014) 9 *PLoS ONE* 9.
- 14 T Rugoho & F Maphosa (n 5) 252.
- 15 M Deluca 'Including children with disabilities in primary school: The case of Mashonaland, Zimbabwe' (2014) *Leonard Cheshire Disability Working Paper* 26 <http://www.ucl.ac.uk/lc-ccr/centrepublishations/workingpapers> (accessed 8 October 2020).
- 16 C Frohmader & S Ortoleva 'The sexual health and reproductive rights of women and girls with disabilities'. Issues paper. ICDP beyond 2014. International Conference on Human Rights
- 17 T Degener 'Disability in a human rights context' (2016) 5 *Laws* 35.
- 18 T Rugoho 'Experiences of disabled commercial sex workers in Zimbabwe in P Chappell & M de Beer *Diverse Voices of Disabled Sexualities in the Global South* (2018) at 151.
- 19 B Connell 'Some parents are more equal than others: Discrimination against people with disabilities under adoption law' (2017) 6 *Laws* 15.

People with disabilities should be free to make such decisions.²⁰ Accordingly, the CRPD mandates governments to promote access to good quality and affordable SRH services to persons with disabilities.²¹ The CRPD also places emphasis on addressing discrimination, inequalities, ensuring participation of persons with disabilities in health planning and decision-making and ensuring accountability. One desired impact of the CRPD is to enable persons with disabilities to claim their rights to information, education and quality of services for SRH.²² Persons with disabilities should be seen as having agency. This has been recognised by United Nations (UN) bodies and many international organisations by mainstreaming SRH for persons with disabilities in their programming. The human rights approach advocates for a substantial shift in how health programming happens, by changing the focus from simply meeting needs to doing so in ways that fulfil human rights.²³

A number of African countries have ratified the CRPD,²⁴ including Zimbabwe, which did so in 2013.²⁵ As might be expected, given the millennia of entrenched stigma that preceded the CRPD, as well as the varying levels of state commitment to its enforcement, progress in implementation differs by location and sector.²⁶ In Zimbabwe, SRH is one area that appears not to be meeting persons with disabilities' expectations. Moreover, there is still a knowledge gap on the extent to which youth with disabilities can achieve their SRH.²⁷

Accordingly, the aim of this study was to explore the sexual expectations and experiences of youth with disabilities in relation to their SRH. Data was collected using a narrative approach which allowed youth with disabilities to recount their own stories. Their responses can inform science and practice. Throughout, this paper employs a rights-based approach in interrogating the barriers faced by youth with disabilities in accessing their SRH.

20 S Hoffman, L Sritharan & A Tejpar 'Is the UN Convention on the Rights of Persons with Disabilities impacting mental health laws and policies in high-income countries? A case study of implementation in Canada' (2016) 16 *BMC International Health & Human Rights* 28.

21 Deluca (n 15).

22 M Ehlers-Flint 'Parenting perceptions and social supports of mothers with cognitive disabilities' (2002) 20 *Sexuality and Disability* 29.

23 B Pinia & ML Conway 'Masculinity and fathering in the lives of rural men with a disability' (2017) 51 *Journal of Rural Studies* 267.

24 J Price 'The seeds of a movement-disabled women and their struggle to organize' 2011 *Women's Rights* available at https://www.awid.org/sites/default/files/atoms/files/changing_their_world_2_-disabled_women_and_their_struggle_to_organize.pdf (accessed 30 March 2020)

25 Rugoho & Maphosa (n 5) 252.

26 M Temmerman, R Khosla & L Say 'Sexual and reproductive health and rights: Global development, health and human rights priority' (2014) 384 *Lancet* 9.

27 T Rugoho & F Maphosa (n 5) 252.

2 Methodology

2.1 Study site

The study was conducted in Chitungwiza, a town located approximately 25 kilometres southeast of Harare, the capital city of Zimbabwe. This town is a densely populated community close to the capital city, but representative of average living conditions in the country. According to the 2012 census, the population of Chitungwiza was around 300 000.²⁸ Due to the collapse of the Zimbabwean economy, many industries in the town have closed, leaving its inhabitants to rely mainly on the informal sector for income.

2.2 Data collection

Data was collected using qualitative methods suitable for generating semi-structured, contextual knowledge on a particular subject.²⁹ We carried out semi-structured interviews with 20 youths with disabilities. Using purposive sampling with the help of a non-governmental organisation that runs outreach programmes for youth with disabilities, 23 people were invited to participate in the research. Of the 20 who agreed, 11 were men and 9 women; their ages ranged from 18 to 33 years. Three (two women and one man) declined to participate; no reasons were sought for their refusal. Although the African Youth Charter defines youth as persons between 15 and 35 years old,³⁰ we selected only those 18 years and older to ensure they were legally regarded as people who could give consent to be interviewed. Three of the participants were visually impaired, two women had a hearing impairment and 15 participants had various physical disabilities. Of the 15 participants with physical disabilities, two used wheelchairs for mobility. Interviewees were asked to narrate their experiences during their upbringing and personal development, especially with regard to their sexuality. Each interview lasted between 45 and 60 minutes. The topics covered in the interviews included: the experience of sexual maturation while living at home and/or attending school; access to information about SRH; finding a sexual partner and developing sexual relationships; getting married; and becoming a parent. All the questions were asked in a very open manner and the respondents described what was relevant and important to them at different times in their lives.

28 MA Stein 'Disability human rights' (2007) 95 *California Law Review* 75.

29 F Mahomed, JE Lord & MA Stein 'Transposing the Convention on the Rights of Persons with Disabilities in Africa: The role of Disabled Peoples' Organisations' (2019) 27 *African Journal of International and Comparative Law* 335.

30 African Union Commission 'The African Youth Charter' (2006) *African Union Commission* Addis Ababa.

To increase validity, a second stage of data collection consisted of two focus group discussions with the same youth with disabilities. For these discussions, we separated men and women into two groups, with the 11 men in one group and the nine women in the other. Each discussion lasted between 70 and 90 minutes. Data collection was carried out by the researchers with the help of a female volunteer research assistant who is well versed in the sign languages used in Zimbabwe. The female assistant researcher, who is 29 years old, collected the data from all female participants during the focus group discussion and interviews. The first author (male) collected data from men. All participants preferred to use Shona, one of the main languages spoken in Zimbabwe; the first researcher is fluent in Shona. In both sessions, participants agreed for the conversations to be recorded using a dictaphone. This was also done to collect the data accurately. Notes were taken to record important points. The same issues were discussed as in the interviews, but now with the interaction and exchange of views in the groups.

2.3 Data analysis

The first author and the research assistant worked together in translating the raw data into English. A colleague who is a professional translator was asked to prepare another translation. The two translations were compared by the first author, research assistant and a professional translator. This improved clarity on the translated data. The next step was familiarisation with data. The first author and research assistant read the data several times. An open coding approach was used to code the data. Data was first put in categories and then emerging themes were listed. The first author and research assistant discussed areas of clarity during the thematic data analysis. The data was further cross-referenced to draw out common and contrasting features and other areas of interest.

2.4 Ethical issues

Great Zimbabwe University provided the ethical approval. The current research adhered to standard ethical research practice³¹ which included obtaining written and verbal informed consent during the planning phase. All participants were told that participation was voluntary (no benefits such as money were to be paid) and that they had the right to exit the research at any point without giving a reason. All the participants agreed with the conditions of the research, and no one opted out. Three participants sought to know how their identities were to be protected. It was explained that anonymity and confidentiality were ensured by giving participants pseudonyms and keeping the data in a secure location.

31 M Deal 'Aversive disablism: Subtle prejudice toward disabled people' (2007) 22 *Disability & Society* 93.

3 Findings

The findings revealed challenges at the different stages of life. The four stages of life identified are: (1) childhood, within the family and at school; (2) becoming sexually active; (3) getting married; and (4) becoming a parent. However, some persons do not necessarily follow the mentioned stages. Results further revealed that discrimination cuts across all stages of life. At the different life stages youth with disabilities used a range of strategies to resist discrimination by choosing to engage in certain behaviours, such as becoming sexually active, getting married and having children. The results are elaborated below.

3.1 Childhood

3.1.1 *Experiences in the family*

Childhood is the stage at which much of the socialisation is done by the family, community and schools. Family, society and schools play a critical role in giving information on SRH. Findings from both focus group discussions and semi-structured interviews with youth with disabilities indicated that they received little information on SRH from home, local society or schools. Participants indicated that the treatment they received from their parents was quite different in comparison to their siblings without disabilities. They highlighted that their non-disabled siblings would get all the necessary information on sexuality and reproductive health from parents, uncles and aunts. A participant with physical disabilities, Chipo, 29 years old, stated:

When my young sister started developing pubic hair and having menstrual cycles she received a lot of information from my mother and aunts ... they started discussing issues of pregnancy and relationships with her. For me, my mother only emphasised issues of hygiene. They treated me as someone without a sexual life. It is hard to seek information from people who discriminate [against] you.

During her semi-structured interview, Edith, 29 years old, who has physical disabilities and is the mother of two children, narrated similar experiences. Persons with disabilities are not seen as sexual persons. She stated:

The only thing I remember my mother teaching me is how to prepare for my menstrual periods. She would evade other questions I would ask her about sexual issues. She warned me that she did not want to hear me talking about sexual issues again. I don't think she thought I would develop sexual desires. Yet she was open to my younger sister.

Participants reported that there was censorship on sexual information for them. While this exists for all children, they noted that when other siblings reach adolescence, they started getting information. By contrast, parents restricted access to information on sexuality for the disabled children – books and magazines were censored before they were allowed to be accessed by youth with disabilities. This experience was shared by a number of participants. During the focus group discussion, Pride, 20 years old with physical disabilities, put it this way:

My parents were against me reading magazines and books on relationships, body parts and sex. They would tell me that this is evil information which would spoil my head, yet other siblings were allowed to read them. Maybe they thought the fact that I am disabled and in a wheel chair meant that I did not have the potential to engage in sexual activities.

The respondents also reported that children with disabilities are discriminated against by their parents who have difficulty accepting their disabilities, thereby making it difficult for them to interact and share information. There is some element of resentment towards children with disabilities by their parents. Edith's parents were always arguing about her disability and accused each other of causing her disability. Neither parent showed affection towards her. Thus, she grew up as a loner, treated as an outcast by both parents. In such an environment it is difficult for children to be open with their parents and ask questions, especially regarding sexual issues.

Anna, 31 years old with multiple disabilities, reported experiences similar to Edith's during her semi-structured interview:

My father hated me. He never allowed me to call him Daddy. He did not acknowledge me as his daughter. In such circumstances, it is difficult to be educated on issues of sexuality and reproductive health. The fact that I was rejected by my parents also made me withdraw from the family and community.

Parents also made it difficult for the community and neighbours to provide their children with information on SRH services. Clara, who is 23 years old with physical disabilities said:

My mother was very [angry] when she heard the girl next door was discussing sexual issues with me. She shouted at her. She further barred her from coming to our house.

Participants further noted that gender could play a role and the treatment experienced by a girl and a boy with disabilities could differ. Thus, some male participants reported that their parents were not that strict on the information that they might access. Calvin, a 24-year old man, and his twin sister were both born with physical disabilities. According to Calvin, their parents monitored his sister more than they did him. He was allowed

to read any book even those on SRH. During a semi-structured interview Calvin said:

My sister was closely monitored. My parents feared that she would become sexually active and become pregnant. Our mother never allowed her to talk about boys. Or read about sexual relationships. But for me, I was treated as a normal boy. They expected me to have girlfriends, marry and have children one day.

Participants agreed that while both boys and girls experienced discrimination in accessing SRH information in comparison to their non-disabled peers, the situation was worse for female adolescents with disabilities. Female participants pointed out that their male counterparts still enjoyed patriarchal benefits. However, other male participants claimed that they also continued to be seen as children because of their disability. Taku, a 24 year old man with cerebral palsy, had this to say during the focus group discussion:

I was treated as an asexual person. Women in my family continued to undress in front of me even when I had become a teenager. No one explained to me about the changes which were happening in my body when I became a teenager. No one even talked to me about sexual issues.

3.1.2 Experiences at school

Children with disabilities were historically educated at special schools, if they attended school at all. These schools did not see SRH education as important. Terrence narrated:

I don't remember any lesson on sexual issues at the school. Actually, it was a subject we were not allowed to utter a word about. The school did not even allow relationships.

The experience was similar for those who went to mainstream schools, when it came to acquiring sexual education. Anna, 31, mentioned:

My teacher in primary school was not comfortable teaching the subject in my presence. Sometime she would ask me to go and sit outside.

3.1.3 Experiences with society and SRH services

Society also makes it difficult for youth with disabilities to access information on SRH services. Participants recalled an outreach programme in which organisations moved around the country teaching people about HIV and AIDS. When they demonstrated condom use, youth with disabilities were forced to leave. Shingi, a 19 year old with both legs amputated, said during his interview:

I vividly remember when the nurses were teaching the community about safe sex methods. One of the elders from the church who was well respected by the community stood up. He argued that it was wrong and sinful to do condom demonstration in my presence. I was asked to leave and my friends remained. The elder said that I was being tortured since I cannot become sexually active. Yet I had made the decision to attend the demonstration on my own.

Edith, 29, added:

The elders in my area did not want to see anyone with a disability during various SRH campaigns. You would be chased away.

Each group indicated that, as a result of this discrimination, they suffered from lack of confidence and low self-esteem when it comes to sexual issues, in large measure because they did not have enough information and had been made to feel it should not concern them by all around them, their family, the schools and the society of the local communities.

However, they made efforts to overcome the discrimination, and to be treated as people with agency to enter into sexual relationships as can be seen in the following sections.

3.2 Becoming sexually active

After childhood, some persons with disabilities wanted to be sexually active. As they looked for sexual partners, their lack of sexual education presented challenges for youth with disabilities. Participants felt that they were not well prepared and lacked capacity to negotiate for sex. Men described that their first experience was filled with uncertainty and anxiety. Paul aged 21, who had both a leg and a hand amputated, asserted during the semi-structured interview:

I was sure that I wanted to do it. But I did not have enough information ... Because I failed the first time, I was embarrassed to try it for the second time. The experience traumatised me because I thought I would not be able to gain an erection again.

The same fear was also by Samson, a 33 year old physically disabled man, who testified during a semi-structured interview:

I started being sexually active at the age of 30. I wanted to have sex as early as 20. Most of my friends started to have sex in their twenties. They would tell me about their sexual escapades. So I would masturbate when I got the opportunity. As a physically disabled person it was difficult to engage in sexual relationships.

Youth reported engaging in sexual activities that exposed them to health risks because they did not have sex education and lacked information on SRH. Jethro, 20 year old, with polio of the left leg, stated that when he

wanted to start having sex he chose a commercial sex worker. The commercial sex worker was open and accommodating to him. However, neither demanded to use a condom, thereby risking infection with a sexually transmitted disease.

For women the experience is not the same. For them, the anxiety was often related to a perceived risk of abuse. They told us they felt that they did not have the power to initiate sexual intercourse in their relationships; they lacked agency in this part of their lives. It was the men who took charge of everything. Rachel felt that she was blackmailed into having sexual intercourse by her first boyfriend who did not have a disability. The boyfriend told her that the only way to show that she loved him was for her to have sex with him. During the semi-structured interview Rachel, aged 21 years, who has a short left arm stated:

I was madly in love with him. I thought he had genuine love for me, yet he wanted to use me. I thought I was fortunate to be loved by someone without a disability. I did not want to sleep with him but he threatened to leave me if I did not. I had to agree to save the relationship. He dumped me a few weeks after sleeping with me.

Again for women in contrast to men, there was anxiety about sharing information on their sexual experiences. Female participants pointed out that when one has not received adequate sexual education, it is also difficult to share sexual experiences, which would otherwise help to maintain wellbeing. The difficulties for persons with disabilities are illustrated by the following stories of Chipo and Samantha. During her interview, Chipo recounted how discrimination and fear of discrimination stopped her sharing:

With the stories of HIV, you would love to share with those close to you so that they can help. My boyfriend and I had intercourse without a condom. I was stressed that I was going to be infected, but there was no one to talk to about that. I remember that one of my childhood friends who is physically disabled shared her story with someone who betrayed her and told the story to others. Her story became known by the entire community. She was labelled and called names. So for me, I was afraid of being shamed.

During her interview, Samantha, 25 years old, with a physical disability, said in a similar vein:

I got my first unwanted pregnancy as a result of the absence of relevant information. When my boyfriend slept with me, we did not use any protection. Of course I was afraid of getting pregnant, but I was afraid to tell my aunt. I could not go to the clinic or pharmacy. I was afraid they would share my story with my aunt. So I kept quiet. My aunt only realised that I was six months pregnant when I felt ill.

Shami, 26 years old, who is hearing impaired, added a comment further illustrating the lonely situation of a disabled person with little knowledge and fear of sharing her experience, during a semi-structured interview:

I developed some pimples around my private area after the first sexual intercourse. The man who had slept with me did not use a condom. I was afraid to share with my mother or sisters. I had to buy the medications in the streets.

Monitoring of sexual activity among younger persons with disabilities was stricter than for other youth. The onset of sexual activity can lead to greater surveillance especially of women. Parents generally did not want their teenage children with disabilities to participate in any sexual relationships. Female participants reported that they were forced to abandon their relationships with their boyfriends due to family interference; they did not want her to have agency in this area of life. As narrated by Edith:

I first had a boyfriend when I was 16 years old. After three months of the relationship my mother found out, after my younger sister told her. My mother was extremely angry. She even told my father and the pastor about my relationship. I was forced to quit the relationship.

In another example of the different treatment of a disabled daughter, Judith said that when her parents discovered that she was sexually active she was interrogated about the men she was sleeping with. Her parents wanted to create a false rape case against her boyfriend. When she refused, confirming that the relationship was consensual, she was forced to go to the rural areas for two years because they thought she would be at less risk of being in a relationship there. Judith, 34 years old with physical disability, reported:

They did not believe that I could enter into consensual sexual relationship. They tried all tricks to stop the relationship.

Women would lose their privacy due to constant policing by family; they also lost the right to consent over their bodies. Women respondents who were sexually active described how their parents forced them to go to the doctor to get medication to prevent pregnancy. They suspected that the medication that was administered to them had long-term effects on their reproduction. Gena, 28 years old, who was diagnosed with a mild form of Down syndrome and cerebral palsy, said:

When my mother realised that I was now sexually active she took me to the doctor. The doctor gave me some medication that could prevent me from being pregnant. All this was done without my consent.

Communities also make it hard for girls with disabilities to become sexually active. Locadia narrated that she entered into a sexual

relationship when she was 21 years old, whilst studying a course in garment making at a vocational college. One of her instructors expressed concern about the relationship. From Locadia's account it was very clear that her instructor treated her as someone who lacked agency, who did not have the right to decide to have a sexual relationship. According to Locadia, a 34 year old woman with spina bifida, the instructor stated:

Why do you need a boyfriend? Are you sure you [were] not forced into that relationship? Do you think they have genuine love for you? Do you think they will marry someone disabled if they impregnate you?

For men the experience was quite different. For them, sharing the information was a positive experience. Engaging in sexual activity is seen as a victory both by them and by their community. Kenneth, a 27 year old with physical disabilities, found acceptance once he told his friends that he was no longer a virgin. He stated:

The experience gave me the masculinity I was lacking. My friends had often portrayed me as a half-man because I had not had sex. They called it the art of taming the opposite sex. So I was excited to let my friends know that I had slept with my girlfriend.

Samson added:

It was a long wait, but I felt as if I were conquering the world. I could boast amongst my peers.

For these men, successfully entering into sexual relationships was a confirmation of their manhood and their adulthood, and an escape from the discrimination they had felt earlier in their youth.

3.3 Getting married

After dating, some persons with disabilities move to marriage. Marriage offers different opportunities. Costs and benefits were compared with regard to selection of a partner. For men it is an opportunity to contest stigma and discrimination. Joe, 27 years old with a physical disability, explained during focus group discussions how he expressed his agency in partner choice:

Dating and marrying able-bodied women reaffirms my manhood and masculinity. For me, a real man should date able-bodied women, even when he is disabled. I had long decided that I was not going to marry a disabled wife like myself.

For Kenneth it took years to reaffirm his masculinity. At first, he would get stressed when his love advances were turned down by able-bodied women. This caused insecurity and anxiety. Kenneth is now married to a teacher

who is not disabled and he feels very comfortable with his wife. He stated during a focus group discussion:

My wife gives me confidence and affirmation. I have been to her work place. She is comfortable with me visiting her work place.

Jonathan, 26 years old, with a physical disability, believes that he married a very beautiful woman and that this status gives him a lot of affirmation. He claimed that because of the beauty of his wife, he had been able to get respect from community members. He believes that the fact that he managed to convince a very beautiful woman to marry him affirms that he is a competent man. He said during a group discussion:

My wife is the most beautiful woman in our suburb. Being married to her gives me a complete sense of self. I do not see myself as a disabled man in a wheelchair but a man like others. She gave me the affirmation I craved.

However, the question of who to marry was met with mixed reactions among the male participants. Others felt that it is prudent to be in a relationship with a fellow disabled woman. They made their decision based on their previous experiences in which non-disabled women abused and cheated on them. Baron said:

They cheat on us these able-bodied women, it is better for me to be married to a disabled woman who equally respects you. I was once cheated by an able-bodied girlfriend. But disabled girlfriends have not cheated me. So I decided to marry a fellow disabled woman.

Baron's sentiments were common also amongst women. Most of the women said they preferred to be married to fellow disabled men. In their opinion, non-disabled men will succumb to negative pressure from their families and community and dump them. These sentiments were shared during a focus group discussion by 26 year old, visually impaired Jessica, who explained:

I feel it's better to be married to disabled men. I have seen many disabled women being dumped by able-bodied men when they finally meet an able-bodied woman.

Jasper, 22 years old, shared the women's view:

Women with disabilities will suffer emotionally if they are married to non-disabled men. Divorce rates are higher among marriages between disabled and able-bodied than in marriages in which both partners are disabled. I have seen it.

Internalised stigma also makes it hard for some people with disabilities to get married to non-disabled partners. Women reported that because of the entrenched discrimination towards them, they feel inferior. The inferiority complex amongst women with disabilities has resulted in their finding it

hard to accept marriage proposals from non-disabled men. Disabled women have a deep-rooted mistrust and suspicion of able-bodied lovers. Olinda, 21 years old, who lost an eye and a hand in an accident, said during her interview:

In a town full of beautiful and nondisabled women like ours, I would take any proposal from men without disabilities with suspicion. When men without disabilities propose to us, the majority of them would want to make fun of us. They do not have any genuine love towards ladies with disabilities. I don't trust able-bodied men.

The participants recognised that they were also victims of internalised stigma, which was common amongst both men and women. They attributed such self-discrimination to their low self-esteem. Shandell, 18 years old, with a physical disability, said during her interview:

Sometimes we are to blame. We create barriers for ourselves. We do not go out there to experiment. We feel self-pity. I have seen most of my friends who think that society hates them, yet it's only their perception.

Arranged relationships and marriages also helped to show that they suffered from internalised stigma. An arranged relationship is when a family or a friend facilitates the person finding a girlfriend or boyfriend; it can result in a marriage. These arrangements may be made by friends or relatives. During a semi-structured interview, Jasper, 22 years old, who has a short hand and a deformed left leg, said:

I had low self-esteem because of my disability and suffered from self-discrimination. My aunt arranged a girl for me. At first, I was tense about the idea but my friends helped me to warm to it. Within a few months, I was happy in the relationship. I am now married to an able-bodied beautiful lady. Looking back, I acknowledge that I was a victim of self-discrimination at that stage in my life.

During her semi-structured interview, Shami, 24 years old with a physical disability, likewise said:

I never thought someone able bodied would love me. I had totally given up on having a sexual life. But after I realised that I was self-discriminating, I started experimenting. My friend pressed me to accept love proposals from one of my colleagues in street vending. After I gave him a chance, he made me happy. He accepted my disability. Even his parents accepted me when he introduced me to them. We are happily married now. I regret all those years of self-discrimination.

3.4 Becoming a parent

Some persons with disabilities will decide to have children either within or outside of marriage. In Zimbabwe, parenthood is an important stage in the lives of youth with disabilities. Parenthood challenges stereotypes, stigma

and discrimination. It enables persons with disabilities to claim the identities of motherhood and fatherhood. They see their children providing them with security in life. Women were proud when those around them began to relate to them as mothers, not as women with disabilities. Shami, 24 years old stated:

I proved the community wrong, they were discriminating me. They regarded me as useless. I have managed to procreate, which is being failed by other able-bodied women. I am now called a mother. I made the decision that I was going to have four or five children to show them that there was nothing wrong with me.

Mellania added:

Having a child gives me the feeling of completeness. I feel that I am a woman just like any other woman. I am now called a mother. Some community members respect me as a mother, as a parent.

Anna, who earlier reported that her parents had resented her for her disability, also reported that after she had three children, the parents changed their attitude towards her. They now treated her as a parent, with the capacity to make decisions.

My parents only started making efforts of getting closer to me after I had children. They now want their grandchildren to visit them. They are now showing me some respect and love.

Similar feelings were shared by men with disabilities. Having children is a demonstration of their fertility. It allows one to get respect from the community. Joe, age 27, said:

My children are a mark of my manhood. How can you claim to be a man without children? Society starts seeing you with a different eye once you are a father.

Jonathan, 26 years old, added:

You gain more status in the community if you have children. I remember that I used to move around with my first son. Just to prove to the community that I was not useless or infertile. I managed to show that my sperm are not disabled also.

Children also bring social capital to the family, as they increase the interaction of their parents with the community. The children have managed to rise above the stigma. Judith said:

My daughter invited me to her school. I interacted with her teachers and other parents. I told them that I sell chickens and peanut butter. I have received several orders. I am now friends with some teachers and parents.

Mellania, 33 years old and a wheelchair user, also felt affirmed by her son's actions. She said:

My son plays soccer for a local junior team. When they are playing with other teams in the district, he invites me to watch him play. He does not care that I am in a wheelchair. I now go out supporting his team frequently. I now have lots of friends. Some offer me transport when my son's team is playing very far; I travel with them in their cars. I am now connected to a number of people. I am now into buying and selling sporting regalia. People support me a lot.

Children also offer emotional support to their parents. They are also seen as potential protectors in future. Anna said:

I receive a lot of emotional support from my children. They comfort me when I complain about the stigma and discrimination that I face from society. They show me much love.

Shami added:

Having children made me happy because they would be able to protect me when they are older. Most people think disabled women do not have the ability to have children, we proved them wrong.

4 Discussion

SRH are now recognised as an integral part of human rights. In recent years, there have been global calls to make SRH information and services accessible to people with disabilities. Using a qualitative methodology, the study explored the sexual expectations and experiences of youth with disabilities. The results showed firstly that from childhood to parenthood, persons with disabilities encounter discrimination. Family, schools and community, which are supposed to be sources of information at the early stages of their lives, continue to discriminate and marginalise them. Similar findings were reported across Africa, for example in South Africa³² where it was also found that parents were not comfortable discussing sexual issues with their children with disabilities. However, this reluctance may also reflect cultural practice and beliefs unrelated to disability. In a study in Kenya on children without disabilities, parents were still not comfortable discussing sexual issues with their children;³³ notably, youth with disabilities may face more general discrimination than other groups.³⁴ This is contrary to article 23 of the CRPD which requires states to implement measures to eliminate discrimination against persons with

32 K Clatos & M Asare 'Sexuality education intervention for parents of children with disabilities: A pilot training program' (2016) 31 *American Journal of Health Studies* 151.

33 J Gupta (n 8) 3.

34 S Ahumuza et al 'Challenges in accessing sexual and reproductive health services by people with physical disabilities in Kampala, Uganda' (2014) 11 *Reproductive Health* 59.

disabilities in all sexual issues such as marriage, family, parenthood and relationships, on an equal basis with others. The study noted, however, that in a family with both boys and girls with disabilities, the boys received better social acceptance when seeking SRH information. Even their participation in sexual relationships was better tolerated. Male youth seem to benefit from the patriarchal system even if they have a disability. The intersection of gender and disability accumulates to further disadvantage the female youth with a disability. Inequities and unfair practices have the potential to affect their self-esteem and well-being in other life stages such as marriage.

An intersection of low education and discrimination affects young women's decisions about seeking medical attention when they perceive an SRH issue. Absence of SRH information could lead to risky sexual behaviour that exposes them to sexually transmitted diseases. Our results also show that many communities are not comfortable with SRH education being offered to youth with disabilities, but they may feel the same about sex education to youth in general; they may believe that teaching youth about sexual issues equates to giving them permission to engage in sex.³⁵ However, when SRH was being discussed at school, youth with disabilities were asked to leave the class. In most societies, elders are not comfortable discussing SRH issues with youths, especially those who have not reached the age to marry.³⁶ The absence of accountability mechanisms in the country makes it hard for youth with disabilities to achieve their SRH rights.

As they mature, youth with disabilities may also enter into sexual relationships just like their peers without disabilities. The onset of sexual activity may bring many experiences to youth regardless of whether they are disabled or not.³⁷ Engaging in sexual activity means different things for men and for women with disabilities. For the men, being sexually active may be part of becoming a man. It shows that they have been able to conquer the negative sentiments that are directed towards them by the community. Male youth with disabilities indulge in sexual activities so that they may fulfil the expectations for a man within the community. Women with disabilities, however, may fear that if they do not agree to sexual activity they will be abandoned by a partner, especially an able-bodied one. Sexual activity may express their desire to please and to demonstrate their love. However, women face more challenges if family and community realise that they have become sexually active. Society will give them negative labels. They may lose control of their autonomy and privacy, as

35 SK Kar, A Choudhury & AP Singh 'Understanding normal development of adolescent sexuality: A bumpy ride' (2015) 8 *Journal of Human Reproductive Sciences* 70.

36 M Boislard, D Van Bongardt & M Blais 'Sexuality (and lack thereof) in adolescence and early adulthood: A review of the literature' (2016) 6 *Behaviour Science* 8.

37 S Offer & B Schneider 'Children's role in generating social capital' (2007) 85 *Social Forces* 1125.

they are monitored constantly on their sexual behaviour. Families are reluctant to let them become sexually active; in extreme cases their fertility is controlled without their input.

At a later stage, persons with disabilities may wish to get married; just as for marriages of non-disabled persons, there is excitement. Results show that it may be used as an opportunity to invalidate myths and stereotypes that are attached to persons with disabilities especially women. Women with disabilities are traditionally seen as incapable of handling the role of a wife.³⁸ Both men and women with disabilities can use marriage to prove to their community that they are able to engage in sexual relationships.³⁹ The choice of a marriage partner is perhaps more critical to persons with disabilities than to other young people. Both men and women gauge the costs and the benefits of different types of partners. The results support the arguments that persons with disabilities have agency and can make sound decisions on getting into a marriage.⁴⁰ Women reported their fear of marrying a non-disabled person, because of perceived risk of abuse, as reported previously.⁴¹ Participants in the current research referred to their past experiences and perceptions to determine who to date and marry. For men, marrying a non-disabled person demonstrates their masculinity. It can be helpful in fighting discrimination and facilitating integration. The choice of a partner can be a result of past discriminations suffered or due to self-discrimination.

Relationships may result in becoming a parent. Parenthood has been seen as a negative experience for persons with disabilities,⁴² but these studies followed the medical model which focuses on the difficulties faced by persons with disabilities as parents.⁴³ Previously, persons with disabilities were also seen as a homogeneous group of people who needed assistance to survive. Persons with disabilities with children were also seen as an economic burden.⁴⁴ However, the women with disabilities in the present study were proud to achieve the identity of mother in their communities, which brought them new respect. Motherhood was important to women with disabilities because it reflects women's female identity.⁴⁵ For the young men, fatherhood can be an opportunity to

38 J Price (n 24).

39 D Anastasiou & JM Kauffman 'A social constructionist approach to disability: Implications for special education' (2011) 77 *Exceptional Children* 367.

40 African Union Commission (n 30).

41 A Daley, S Phipps & NR Branscombe 'The social complexities of disability: Discrimination, belonging and life satisfaction among Canadian youth' (2018) 5 *SSM – Population Health* 55.

42 MA Feldman et al 'Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities' (2002) 15 *Journal of Applied Research in Intellectual Disabilities* 314.

43 M Parchomiuk 'Social context of disabled parenting' (2014) 32 *Sexuality and Disability* 231.

44 Ehlers-Flint (n 22).

45 Z Lin & L Yang 'Denial of disability discrimination by disabled people in China' (2018) 33 *Disability & Society* 804.

demonstrate their masculinity, as reported earlier.⁴⁶ It boosts the self-esteem of persons with disabilities as it improves their integration into the community through the social networks established through their children. Children help in establishing networks which becomes a source of social capital for their parents as described before.⁴⁷ The current study also showed that children could offer emotional and social support to their parents when they perceive discrimination.

Discrimination against people with disabilities has remained the biggest challenge in all spheres of life.⁴⁸ The study results show that youth with disabilities experienced discrimination at every stage in their life cycle. This discrimination may affect their wellbeing, as has been reported. Women with disabilities were likely to be more affected by discrimination. This could be attributed to the intersectionality of disability, gender, economic status and other factors which promote inequalities against women with disabilities. Women often have a subservient role in many countries, including Zimbabwe, but having a disability exacerbates that situation; women with disabilities are victims of multi-discrimination. It is because of this reason that the UN Committee on the Rights of Persons with Disabilities has emphasised that governments should promote the SRH rights of women with disabilities. Results show that years of suffering discrimination can result in self-stigma, which was also reported by the participants in this research, for example as a limiting factor in finding a partner to date or to marry. However, the results also showed many examples of the persons with disabilities expressing agency in finding information, finding sexual partners, getting married and having a family. Many of them were able to overcome the discrimination and self-stigma to participate in the social life of their community.

The current study was conducted in Chitungwiza which is a dormitory town outside the capital city of Harare. The authors expected better understanding of disability issues because of social amenities such as schools which are found in the area. There are also a number of disabled peoples' organisations and non-governmental organisations working in the areas on disability, so one might have expected better treatment of persons with disabilities as well. Youth with disabilities in other countries in Southern Africa with similar cultures and levels of development may be facing the same types of barriers, and strategies to reduce those barriers may be applicable not only within, but also outside of Zimbabwe.

46 Pinia & Conway (n 23).

47 D Anastasiou & J Kauffman 'Disability as cultural difference: Implications for special education' (2013) 33 *Remedial and Special Education* 139.

48 L Rothstein 'A primer on disability discrimination in higher education' (2018) 7 *Laws* 25.

5 Conclusion

From a rights-based approach, it is clear that communities have not yet created a friendly environment for youth with disabilities to achieve their SRH. Zimbabwe was the first country in Africa to have a disability-related law, however, people with disabilities have not yet enjoyed the rights enshrined in that law. This can also be said with the education where a number of people with disabilities are out of schools. Lacking support, youth with disabilities are becoming sexually active without accurate information and knowledge to protect them from health risks. It is recommended that full operationalisation of the CRPD and the Protocol to The African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa⁴⁹ be implemented, to improve the promotion of sexual and reproductive health of youth with disabilities. The country also needs to establish accountability mechanisms that can be used by persons with disabilities.

49 African Union 'Protocol to The African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa' (2018).