Women with Intellectual Disability and Access to Reproductive Health Information: A Case Study

By: Million Shiferaw Kebede

School of Social Work
Addis Ababa University

November, 2014
Addis Ababa

Women with Intellectual Disability and Access to Reproductive Health Information: A Case Study

By: Million Shiferaw Kebede

School of Social Work
Addis Ababa University

November, 2014
Addis Ababa

Women with Intellectual Disability and Access to Reproductive Health Information: A Case Study

By: Million Shiferaw Kebede

Advisor: Mengistu Legesse (PhD)

A Thesis Submitted To School of Social Work, Addis Ababa University

In Partial Fulfillment of the requirements for the degree of Masters in Social Work (MSW)

School of Social Work

Addis Ababa University

November, 2014

Women with Intellectual Disability and Access to Reproductive Health Information: A Case Study

By: Million Shiferaw Kebede

Graduate School Of Social Work Approval of board of examiners

Chair person, Department Graduate Committee Signature

Mengistu Legesse

Advisor Signature

Dr. Comdr. Demelash Kassaye

Examiner Signature

Dr. Sewalem Tsega

Examiner Signature

Acknowledgment

Primarily, praise to my Lord and Savior Jesus Christ for all his blessings.

I want to say thank you to my advisor Mengistu Legesse (PhD), for he has guided me throughout this research with patience and diligence.

I am grateful for the nonstop encouragement from my father, my mother, my sister and my brother.

My deepest gratitude goes to women with intellectual disability who received me with open arms and trusted me enough to share their most personal stories. I am indebted to their families as well, who welcomed me to their homes and helped me in every way possible. To the mothers, who carry every burden of protecting their daughters, I want to say thank you for showing me how far a woman goes for her children.

Finally, yet importantly, I would also like to thank staffs of ENAID for introducing me to such wonderful women, for allowing me to use their office and for extending their support whenever required. This research would not have been possible if it were not for their positive and heartfelt cooperation.

Abstract

This qualitative research describes the challenges women with intellectual disability face in relation to their reproductive health using case study method. For this purpose, 10 case study participants who are women with mild and moderate intellectual disability and are members of Ethiopian National Association of Intellectual Disability (ENAID) were interviewed using in-depth interview method. Two Focus Group Discussions (FGDs) were conducted with two groups of parents/guardians. Each of the FGD groups had six participants. In addition to these, four staffs of ENAID were interviewed and three guardians of women with intellectual disability were key informants throughout the study. The findings of the research indicated that stereotypes about sexuality of women with intellectual disability has restricted them from expressing their sexuality, limited their access to information about sex, unwanted pregnancy, contraceptives, sexually transmitted infections and methods of prevention, limited their access to reproductive health services and contributed to their vulnerability to sexual abuse. In conclusion, although the nature of their disability has an impact on their day-to-day life, women with intellectual disability also have a unique way of learning and understanding their social environment. They learn ways of behaving and carrying out specific tasks through repeated and simple instructions and take more time to understand and process new information than other people without intellectual disability. Hence, by focusing on their ability, special considerations should be given about what kinds of methods are appropriate to their specific disability in order to teach them about their sexuality and their sexual health.

Key words: intellectual disability, mild and moderate intellectual disability, sexuality, sexual health, reproductive health.

Tables and Figures

Tables **Page**

Figures

Acronyms

AAIDD: American Association of Intellectual and Developmental Disabilities

AIDS: Acquired Immunodeficiency Syndrome

APA: American Psychiatric Association

DSM: Diagnostic and Statistical Manual for Mental Disorders

ENAMRCY: Ethiopian National Association of Mentally Retarded Children and Youth

ENAID: Ethiopian National Association of Intellectual Disabilities

FGDs: Focus Group Discussions (FGDs)

HIV: Human Immunodeficiency Virus

HRW: Human Rights Watch

ICPD: International Conference on Population and Development

IPPF: International Planned Parenthood Federation Charter identified twelve rights

JICA: Japan International Cooperation agency

MDGs: Millennium Development Goals

MIUSA: Mobility International USA

SRH: Sexual Reproductive Health

STIs: Sexually Transmitted Infections

UN: United Nations

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

WHO: World Health Organization

WB: World Bank

Table of contents

Contents **Page**

CHAPTER ONE

CHAPTER TWO

CHAPTER THREE

CHAPTER FOUR

CHAPTER FIVE

REFERENCES

APPENDICES

CHAPTER ONE

Introduction

Background

Different studies estimate the number of Ethiopians living with disability. For instance, a study by Japan International Cooperation Agency estimates 7.6% (about 6.2 million) of the population lives with a disability (JICA, 2002). While, WHO and WB estimated 17.6% of (16 million) Ethiopians live with disability (WHO & WB, 2011). However, the national population census puts prevalence rate of disability 1.09% (805,492) (Census, 2007). Although there is an observed discrepancy in statistical representation of persons with disabilities, they are still significant members of the society and deserve equal attention from the government and other non-governmental agencies.

In his book 'Disability in Ethiopia', Tirussew Teffera cites a baseline survey on disability by Taddess et.al that revealed the prevalence of disability in Ethiopia to be 2.95% and women with disabilities make up 44.2% (Teferra, 2005). When discussing the magnitude of disability according to disability type, Tirussew puts the magnitude of persons with cognitive disability 6.5% (Teferra, 2005). This category includes persons with mild, moderate and profound intellectual disability. According to the national census, there are 41,487 persons with intellectual disability in Ethiopia and 17,904 or 43.16% are women (Census, 2007). From the total number of persons with intellectual disability, 2,550 (6.15%) of them live in Addis Ababa (Census, 2007).

Persons with disabilities have various unmet psychosocial and economic needs. However, the focus of this research is limited to and only discusses reproductive health of women with intellectual disability with respect to the challenges they face.

Persons with disabilities have the same sexual and reproductive health needs as other people. Improved access to reproductive health services to address sexual and reproductive health is one of the societal needs that have to be available for all members of the society including these women. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that persons with disabilities deserve to attain the highest standard of health care without discrimination (UNCRPD, 2006).

Women with intellectual disability's access to proper reproductive health information and services is very limited due to stereotype about their sexuality, the nature of their impairment, the stigma attached to it, capacity of service providers to handle such kind of cases and the focus intellectual impairment receives from policy makers as well as interventionist.

Sexuality is part of being a human. Women and men with disabilities have the same experiences as persons without disability on the matter. However, stereotypes about the sexuality of people with disabilities in general and women with intellectual disability in particular are among the barriers that contribute to inaccessibility of reproductive health information and services to women with intellectual disability. The common stereotypes include; people with disabilities will forever remain childlike, are and always will be asexual , are unable to understand their sexual desires, have incontrollable sex drives and are potential sexual deviants, and should be denied sex education in case it 'gives them ideas' (http://www.sexualityandu.ca/teachers/teaching-sex-ed-for-youth-with-intellectual-disabilities).

> "Women with intellectual disability experience the same range of sexual thoughts, attitudes, feelings, desires, fantasies and activities as anyone else. To understand and enjoy sexuality, everyone needs adequate information and support from a young age" (BetterHealth, 2014, p1).

Hence, women with intellectual disability should have the chance to explore their sexuality and have access so reproductive health information and services.

Considering their vulnerability to sexual health problems, there is limited research to assess the challenges women with intellectual impairment face in accessing information and services related to sexual reproductive health services including HIV/AIDS. In addition to this, identifying barriers contributing to lack of reproductive health information and services accessibility is essential. This paper tries to contribute to addressing this gap by identifying the sexual health problems faced by women with intellectual disability. In doing so, the researcher hopes to initiate the focus of other researches towards reproductive health needs of women with intellectual disability and eventually contribute to lobbying for access to disability tailored reproductive health information and services.

Statement of the problem

Women with disabilities are defined by both their sex and their impairment. In a society that is still fighting gender inequality, being a woman with impairment means facing double burden of gender and disability. A study by Women with Disability Australia describes how women with disabilities and men with disabilities have different life experiences due to biological, psychological, economic, social, political and cultural attributes associated with being female and male (WWDA, 2011). These different experiences affect the life of women with disabilities in different ways. For instance, women with disabilities face multiple discriminations and are often more disadvantaged than men with disabilities in a similar circumstance (WWDA, 2011).

According to International Network of Women with Disabilities (INWD), gender inequalities are the bases for violence against women and women with disabilities are affected more due to their disabilities. Hence, violence against women with disabilities are both gender and disability-based (INWD, 2011). Another study by Astbury and Walji asserts that although women with disabilities face similar forms of violence, they experience much higher levels of all forms of violence than non-disabled women do (Astbury & Walji, 2013).

Women with disabilities are often denied equal enjoyment of their human rights, in particular by virtue of the lesser status ascribed to them by tradition and custom, or as a result of overt or covert discrimination (WWDA, 2011). Women with disabilities face particular disadvantages in the areas of education, work and employment, family and reproductive rights, health, violence and abuse (ibid).

Women with disabilities are more vulnerable and there is a challenge for them to access services due lack of disability mainstreaming and inclusion in social, legal and health services (Astbury & Walji, 2013).

Human Rights Watch (HRW) report on 2010 asserts an increasing number of women and girls with disabilities are denied reproductive and sexual rights through the practice of forced sterilization worldwide (HRW, 2010). Attitude of society that pity person with disability and characterize disability as a personal tragedy or matter for medical management and rehabilitation is one of the main reasons for forced sterilization. In addition to this, some women and girls with disabilities may have difficulties in understanding or communicating what was done to them increases their vulnerability to forced sterilization.

Women with disabilities are particularly vulnerable to HIV infection, especially unlikely to have access to antiretroviral drugs and are frequently abandoned by their partners, and each new partner brings a heightened risk of HIV infection (HRW, 2010). The negative attitudes of services providers and society members' wrong and stigmatizing beliefs add to the discrimination of women with disability and limit their equal access to health services.

People with intellectual disability experience the same range of sexual needs and desires as other people but often they experience many difficulties meeting their needs, they may not be able to communicate or act on these desires, and may struggle with learning appropriate sexual behavior (Eastgate, 2008). Easgate argues that people with intellectual disability face a high risk of sexual abuse and they are likely not to be offered the full range of choices for contraception and sexual health screening.

According to Frehomader and Ortolena, systemic prejudice and discrimination against women with disabilities contributes to the multiple and extreme violations of their sexual and reproductive rights (ICPD, 2013).

Although this challenge is common to all women with disabilities, women with intellectual disability face problems specific to their intellectual impairment while accessing reproductive health services.

> "For many adults with an intellectual disability, some assume that they do not need information about safer sex or contraception, as it is understood to be unlikely they will have sex. This withholding or selective provision of information is in direct contravention of a person's rights to access information that can support positive sexual experiences and health. Indeed, maintaining silence may increase vulnerability to sexual exploitation, unplanned pregnancy, problematic sexual behaviors and sexually transmitted infections" (Sexual Health & Family Planning Australia, 2013, p9)

A report by Aging Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) states that women with intellectual disability have the same sexual needs and rights however, in many societies, general attitudes toward persons with disabilities and toward women specifically may further serve to deny or trivialize sexual health concerns (IASSID, 1999). Unfortunately, such attitudes may also carry over to women of older age and thus deny access to health services related to gynecological concerns and functions and may lead to a dearth of health professionals who are willing or trained to address reproductive health issues (ibid).

Objectives

General objective

Describe problems women with intellectual disability face in accessing appropriate sexual reproductive health services:

Specific objectives

1. Identify problems of women with intellectual disability in relation to sexual reproductive health.
2. Identify barriers that hinder intellectually disabled women's access to reproductive health information and services.
3. Recommend ways to improve intellectually disabled women's access to reproductive health and information services.

Purpose of the Study

This research tries to describe major sexual health problems women with intellectual impairment by focusing on attitudinal, communication, institutional, physical and environmental barriers that limit accessibility of HIV/AIDS and SRH information and services. In addition to this, the research explores ways of facilitating accessibility of information services and the contribution of different government sectors, non-governmental organizations and civil associations. In doing so, the researcher hopes to advocate for the rights of women with intellectual disabilities to have access to HIV/AIDS and SRH health information and services.

Research questions

In light of the purpose of the study, which is going to describe the sexual reproductive health problems women with intellectual disabilities face, the following were the research questions in this study.

- ✓ What are the problems women with intellectual impairment face in relation to reproductive health?
- ✓ What are the barriers that limit women with intellectual impairment to access reproductive health information and services?
- ✓ What kind of measures are needed to improve sexual health problems of women with intellectual impairment?

Significance of the Study

In September 2000, 189 United Nations member states including Ethiopia, signed the United Nations Millennium Declaration where 'The United Nations Millennium Development Goals' was derived from. These Millennium Development Goals (MDGs) comprise of eight targets for member states to achieve by the year 2015. Among the eight goals, reducing child mortality, improve maternal health and combating HIV/AIDS calls for improvement in relation to information and service accessibility in the area of reproductive health. In addition to these, promoting gender equality and empowering women is another MDG.

The countries since then have been working different directions to achieve these MDGs. There is effort from the Ethiopian government, non-governmental organizations and associations to improve access to HIV/AIDS and SRH information and services.

On December 13, 2006, United Nations member states adopted the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that was available for signature at United Nations Headquarter in New York on March 30, 2007 (www.un.org/disabilities/convention/signature.shtml).

The articles in the convention promote equal access and participation of persons with disabilities in social, cultural, economic and political arenas without discrimination (UNCRDP, 2007). Ethiopia signed and ratified the convention on March 30, 2007 and July 7, 2010 respectively (www.un.org/disabilities/countires.asp?navid=17&pid-166) and has the responsibility to uphold its contents. The constitution of the Federal Democratic Republic of Ethiopia and series laws regulations and laws derived from it also promote equality and empowerment of persons with disabilities in general.

Different studies estimate the number of Ethiopians living with disability. For instance, a study by Japan International Cooperation Agency estimates 7.6% (about 6.2 million) of the population lives with a disability (JICA, 2002) while according to the World Health Organization (WHO) and the World Bank (WB) disability report, an estimated 17.6% of (16 million) Ethiopians live with significant disability (WHO & WB, 2011). The national population census puts prevalence rate of disability 1.09% (805,492) (Census, 2007) while 1994, it was 1.85%.

Table 1

Magnitude of disability according to specific disability type

Disability type	Magnitude
Motor disorder	41.2%
Persons with visual impairment	30.4 %
Persons with hearing impairment	14.9 %
Persons with cognitive disability (with mild, moderate and profound intellectual disability)	6.5 %
Persons with speech and language impairment	2.4 %
Persons with behavioral problems	2.4 %
Persons with multiple impairments	2 %

Source: Adopted from Tirusew Teferra, 2005.Disability in Ethiopia: Issues, Insights and Implications. Addis Ababa University Printing Press, p3.

Due to the international and national interest in protecting vulnerable groups and improving their access to the country's resources, there is a continuing effort from the Ethiopian government, non-governmental organizations and associations to improve access to HIV/AIDS and SRH information and services.

When speaking about the reproductive health right of persons with disabilities and consequently their right to equal access to information and services, we are addressing one area of equal access and participation without discrimination.

Hence, the issue of disability, person with disability and their access to services is a current and pressing issue to be well researched and advocated. In addition to this, the issue directly relates to the social work profession. As the definition by the International Federation of social workers states:

> “social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. Utilizing theories of human behavior and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work" (IFSW, 2001).

Considering this, the issue of persons with disabilities is pivotal to social work profession and research in social work. The issues of persons with disabilities in general and women with intellectual disabilities in particular should be given due attention by policy makers and human service providers.

Limitations of the Study

When looking at statistical data and research related to disability, global studies and researches are available more easily than locally and nationally focused studies. Intellectual disability by itself is concept yet to be well understood by practitioners and service providers. Hence, one major limitation was availability of local statistics and researches related to intellectual impairment and reproductive health.

Since this research is a case study and focuses only in selected locations in Addis Ababa, there may be a problem of generalization. Furthermore, the study focuses on describing the challenges faced by women with intellectual disability through collection of information from women with intellectual disability and their families primarily. Hence, due to the nature of the participants’ disability and the sensitivity of the topic, there were communication problems that arose on the course of data collection.

Definition of Terms

Impairment and disability

As defined in the convention for the rights of persons with disabilities, disability is long-term physical, mental, intellectual or sensory (vision & hearing) impairment which in interaction with various barriers may hinder full and effective participation in society on an equal basis with others (UNCRPD, 2006). When we say impairment, it refers to limited or total loss of functioning in parts or organs of the body (UNCRPD, 2006). The basic conceptual difference between impairment and disability is impairment is restricted to loss of functioning of the body parts, while disability occurs when the individual with impairment interacts with the social environment and his/her equal participation is limited due to social, environmental or political barriers. Therefore, persons with disabilities are those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (UNCRPD, 2006).

Intellectual disability

People with intellectual disability are people who have developed intellectual impairment before the age of 18 and exhibit either form or types of intellectual impairment.

According to the definition by the American Association of Intellectual and Developmental disabilities (AAIDD), intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. (http://aaidd.org/intellectual-disability/definition#.U1-jJKxZ4lc). The AAIDD also further defines intellectual functioning and adaptive behavior as follows,

> "intellectual functioning—also called intelligence—refers to general mental capacity, such as learning, reasoning, problem solving, and so on. One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning. Adaptive behavior is the collection of conceptional, social, and practical skills that are learned and performed by people in their everyday lives. There are standardized test used to measure limitations in adaptive behavior" (http://aaidd.org/intellectual-disability/definition#.U1-jJKxZ4lc)

The level of impairment differs from individuals to individuals based on its severity. The American Psychiatric Association (APA) published the Diagnostic and Statistical Manual for Mental Disorders (DSM-5), which is used by clinicians and researchers as a standard criteria for classification of mental disorders. The diagnosis of intellectual disability was revised from mental retardations in DSM-5 from previous manual. The various levels of severity have to be defined on the basis of adaptive functioning not just IQ measures, because it is adaptive functioning that determines the level of supports required (Tassé, 2013). Citing DSM-4, Cheung gives the following categories to describe the levels of severity based on IQ; mild intellectual disability, which is demonstrated by an IQ level of 50–55 to approximately 70; moderate intellectual disability, which is shown by an IQ of 35–40 to 50–55, severe intellectual disability, which is evidenced by an IQ of 20–25 to 35–40 and profound intellectual disability, which is illustrated by an IQ below 20 or 25.4 are used to describe these levels (Cheung, 2013).

Referring to the DSM-5 severity code, Reynolds et.al gives the following comprehensive severity level (http://sevencounties.org/poc/view_doc.php?type=doc&id=10351&cn=208)

- ✓ Mild intellectual disability includes about 85 percent of people with intellectual disabilities. Many individuals within this group can achieve some academic success.

They usually meet elementary academic levels or beyond with sufficient supports. People with this degree of severity are mostly self-sufficient with sufficient supports. In many cases, they can live independently within their communities with a minimal level of additional supports. These supports might include assistance with life decisions. Additional time, instructions, and reminders may be needed for other life skills such as finances, nutrition, shopping, and transportation.

- ✓ Moderate intellectual disability includes around 10 percent of the individuals with intellectual disabilities. People in this range have adequate communication skills but complexity is more limited. Social cues, social judgment, and social decisions (particularly romantic decisions) regularly need support. Most self-care activities can be performed but may require extended instruction and support. Independent employment can be achieved in positions that require limited conceptual or social skills. However, additional supports may be required. Likewise, independent living may be achieved with moderate supports such as those available in group homes.
- ✓ Severe intellectual disability describes 3 to 4 percent of this population. Communication skills are very basic. Self-care activities require daily assistance. Many individuals in this category will require safety supervision and supportive assistance. Residence in supported housing is usually necessary.
- ✓ Profound intellectual disability describes a very small portion of the persons with intellectual disabilities. Only 1 to 2 percent fall into this category. This person is dependent upon others for all aspects of daily care. Usually 24-hour care and support are needed. Communication skills are quite limited. People with profound intellectual disability usually have co-occurring sensory or physical limitations.

Women with intellectual disability

Women with intellectual disability are those women who exhibit one of the above mentioned levels of intellectual impairment. For the purpose of this study, women with mild and moderate intellectual disability are generally referred to as women with intellectual disability throughout this paper.

Disability inclusive reproductive health services

Having equal access to health services regardless of one's social, economic and political status is a basic human right. However, this principle of equal participation may not be followed due to discriminatory practices where individuals and groups are left behind or ignored just because they represent a 'minority'.

Inclusion is about everyone and not leaving anyone behind hence, it is not just about persons with disabilities. However, disability inclusion means equal opportunities for all persons in spite of disabilities. It also means persons with different impairments should be able to participate in every aspect of life e.g., education, employment, health, basic services regardless of their impairments. Therefore, inclusive development ensures that persons with disabilities are recognized as rights-holding equal members of society, whose needs and concerns are addressed in the design, implementation and evaluation of all policies, projects/programs at all levels (Handicap International, 2011).

The World Bank defines inclusive development as the result of a combination of principles and processes of inclusion, equity and access (Guernsey et al., 2006).

Inclusion: persons with disabilities should be accepted as equal partners in development and included as full participants in all development activities

Equity: persons with disabilities should enjoy equitable access to the benefits resulting from development activities. In addition, development activities should promote non-discrimination and equal opportunities for persons with disabilities to participate in every facet of life – civil, political, economic, social and cultural

Access: persons with disabilities should enjoy access to the built environment, transportation, information, and communications infrastructure, so that they can participate in all aspects of life and thus enjoy the full range of human rights.

Hence, pre-existing reproductive and HIV/AIDS services have to be inclusive of persons with disabilities. Since people have different impairments, the inclusion process should also address the impairment type of all people with disabilities. Disability inclusive reproductive health services are those who have integrated the needs of persons with disabilities in their planning, programming and service delivery systems. Universal design has to be central part of inclusion process. Universal design according to the UNCRPD is the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed. (UNCRPD, 2006)

CHAPTER TWO

Literature review

Poverty and disability

As previously mentioned, WHO and WB over a billion people or 15.6% of the world's population live with a significant disability (WHO&WB, 2011), making them world's largest minority group (UN, 2006). People with disability are found both in developing and developed countries. However, the proportion of people with disabilities living in developing countries is than those in developed parts of the world. According to world disability report, 80% of people with disabilities live in developing countries (WHO&WB, 2011). Moreover, 1 in 5 of the poorest of the poor living in developing countries has a disability (Elwan, 1999).

These and other studies show that there is a strong link between poverty and disability. Poverty is said to be both a cause and consequence of disability. Poverty and disability reinforce each other, contributing to increased vulnerability and exclusion that the majority of people with disabilities find their situation affects their chances of going to school, working for a living, enjoying family life, and participating as equals in social life (DFID, 2000).

Department for International Development (DFID) on its issue paper disability poverty and development, also estimates that only 2% of people with disabilities in developing countries have access to rehabilitation and appropriate basic health services (DFID, 2000). Poverty also directly affects people with disabilities access to health services.

Poor families do not have adequate income to fulfill their basic needs and access to health care is very limited (Elwan, 1999). Often poor families may not have the financial capacity to seek treatment for otherwise potentially disabling diseases. This lack of adequate and timely health care can make health conditions of people with disabilities worse and can turn impairments into chronic disabilities (Elwan, 1999).

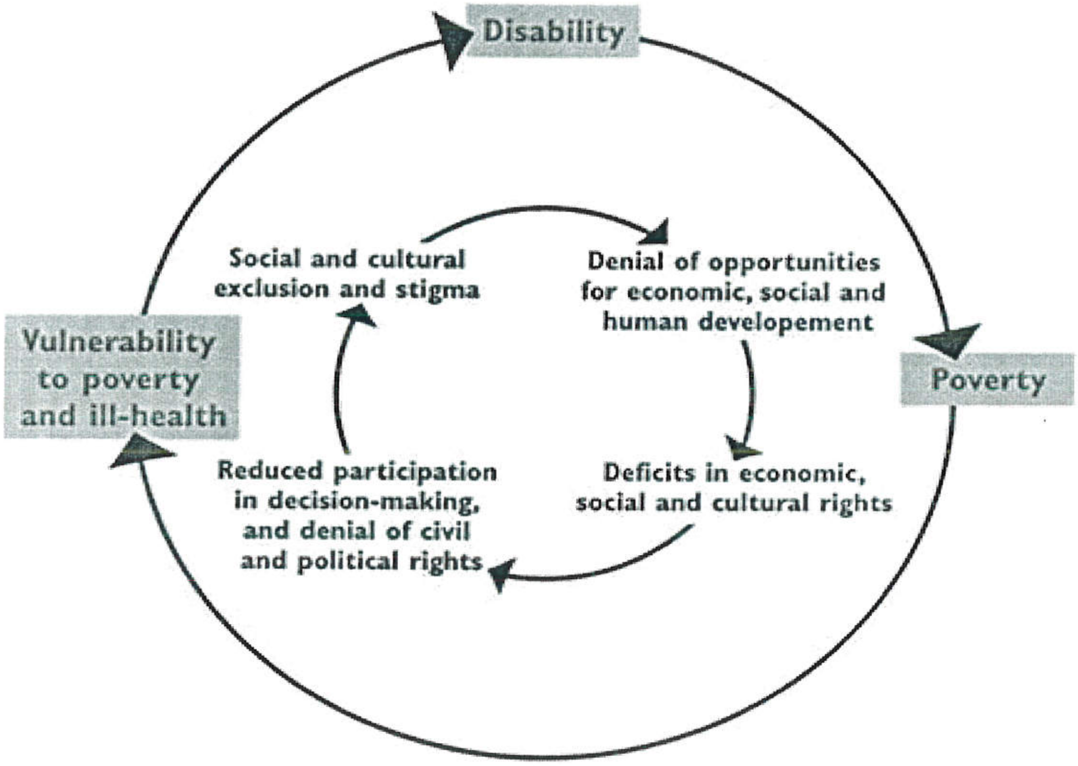

Figure 1: Cycle of poverty, disability and vulnerability

Source: Adopted from Department For International Development.2000.Disability, poverty and development,p.4.

Gender and Disability

The interplay between gender and disability and the effect it has on the rights of women with disabilities to be protected from discrimination and abuse as well as have equal access social and health services has been studied by interest groups, activists and Disabled Peoples Organizations (DPOs). The following are few selected studies that show how women with disabilities face double challenges due to their gender and disability status. Women with disabilities are among the poorest of the poor that adds to their minority status where the burden they face sometimes is tripled.

Using a human rights approach, a study by Women with Disabilities Australia (WWDA, 2011) gives a comprehensive assessment of the situation of women with disabilities by stressing the relationship between gender and disability and human right principles. Accordingly, gender classification is seen as one of the most important categories of social organization. Although people with disabilities in general are often treated as asexual, genderless human beings, women with disabilities and men with disabilities have different life experiences due to biological, psychological, economic, social, political and cultural attributes associated with being female and male. Women with disabilities face multiple discriminations and are often more disadvantaged than men with disabilities in similar circumstances. Women with disabilities are often denied equal enjoyment of their human rights, in particular by virtue of the lesser status ascribed to them by tradition and custom, or as a result of overt or covert discrimination. Women with disabilities face particular disadvantages in the areas of education, work and employment, family and reproductive rights, health, violence and abuse.

A paper published by the International Network of Women with Disabilities (INWD) in 2011, focuses on violence against women with disabilities. It shows how gender inequalities are the bases for violence against women and how women with disabilities are affected more due to their disabilities. The paper argues that violence against women is a human rights violation and forms of violence experienced may differ depending on culture or socioeconomic standing, there are aspects of violence that are universal. The study suggests that although women with disabilities experience violence experienced by all women, some gender-based violence against them are ignored due to discrimination based on disability. Hence, it concludes that violence against women with disabilities are both gender and disability-based. Studies show that persons with disabilities are victims of abuse on a far greater scale than persons without disabilities.

Another research reviewed about gender based violence against women with disability is a research paper by Astubury and Walji. This research elaborates on how Cambodian women with disabilities experience multiple disadvantages compared to their fellow non-disabled women due to the interplay between gender, disability and poverty. It found that although women with disabilities faced similar forms of violence, they experience much higher levels of all forms of violence than non-disabled women (Astbury & Walji, 2013). The paper also shows how women with disabilities are more vulnerable and how there is a challenge for them to access services due lack of disability mainstreaming and inclusion in social, legal and health services.

Women with disabilities hence are discriminated on the bases of their disability and gender and sometimes their social status, which limits their access to social, and health services.

Reproductive health problems of women with intellectual disability

There are barriers that act as factors for the inaccessibility of services. Focusing on women with disability access to reproductive health information and services, studies have been conducted on reproductive health problems and challenges women with disabilities face. The following are selected literatures written on the issue at hand.

On addressing the human rights of women and children with disabilities, Human Rights Watch (HRW) report on 2010 asserts an increasing number of women and girls with disabilities are denied reproductive and sexual rights through the practice of forced sterilization worldwide. The report defines forced sterilization as carrying out a sterilization procedure while a person expressly refuses to undergo the procedure or without her knowledge or she is not given an opportunity to provide consent (HRW, 2010). Particularly women with intellectual disability According to the report, pregnancy prevention, menstrual management and personal care, are the premises used to justify the act. Attitude of society that pity person with disability and characterize disability as a personal tragedy or matter for medical management and rehabilitation is one of the main reasons for forced sterilization. In addition to this, some women and girls with disabilities may have difficulties in understanding or communicating what was done to them increases their vulnerability to forced sterilization.

The report asserts that women with disabilities are particularly vulnerable to HIV infection, especially unlikely to have access to antiretroviral drugs and are frequently abandoned by their partners, and each new partner brings a heightened risk of HIV infection. Negative attitudes of services providers that makes them discriminatory and hostile towards women with disabilities is among the challenges in providing appropriate health services. Service providers often make derogatory remarks, including questioning why a woman with a disability would ever engage in sex or have a child. In addition to the negative attitudes held by services providers, society members' wrong and stigmatizing beliefs also add to the discrimination.

Although research shows that women with disabilities are sexually active and engage in same kind of sexual activities as non-disabled women, many societies hold the assumption that women with disabilities are asexual and therefore are free of HIV/AIDS. In high HIV-burden African countries, myths persist that sex with a virgin can cure AIDS, making women and girls with disabilities targets of sexual violence.

Women with disabilities are less likely to receive information about HIV prevention and safe sex, and are less likely to have access to prevention methods such as condoms. This is due lack of disability mainstreaming and inclusion sexual and reproductive health education and services.

In her article about sexual health for people with intellectual disability, Gillian Eastgate argues that people with intellectual disability experience sexual needs and desires, just as do other people. Wrong beliefs and negative attitudes in the community where people with intellectual disability are perceived as either childlike and asexual, or 'oversexed' and likely to become sex offenders makes it difficult or impossible for adults with intellectual disability to express their sexuality because of inadequate community support, or because a person's own support needs are too high (Eastgate, 2008). Eastgate further points out common sexual health problems faced by people with intellectual disability. These include, lack of awareness about appropriate sexual behavior, lack of access to information about use of contraceptives and lack of decision making with this regard, vulnerability to STIs and lack of access to accessible reproductive health information and services and menstrual management and sterilization.

Reproductive health right of women with disability

In 1995, IPPF produced its Charter on Sexual and Reproductive Rights, which identified 12 core rights based on international human rights instruments relevant to sexual and reproductive health (IPPF, 2003). According to the IPPF, sexual and reproductive rights are rights and freedoms pertaining to individuals as well as to couples (IPPF, 2003).

The twelve core rights identified on the charter were; the right to life, the right to liberty and security of the person, the right to equality, and to be free from all forms of discrimination, the right to privacy, the right to freedom of thought, the right to information and education, the Right to choose whether or not to marry and to found and plan a Family, the right to decide whether or when to have children, the right to health care and health protection, the right to the benefits of scientific progress, the right to freedom of assembly and political participation and the right to be free from torture and ill treatment (IPPF, 2003).

Women with disabilities are as well entitled to these rights regardless of their disability status. The UNCRPD states reproductive health rights of persons with disabilities in the following articles, which complements IPPF's charter on sexual and reproductive health rights.

- ✓ Article 12 of the Convention ensures that people with disabilities can make their own choices, including when it comes to fertility and medical procedures, by providing a right to "enjoy legal capacity on an equal basis with others in all aspects of life." When medical procedures are performed without authorization, this can be a form of torture or other cruel, inhuman, or degrading treatment
- ✓ Article 15 of the Convention requires that health services for persons with disabilities be "gender-sensitive" while providing "the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs."
- ✓ Article 23 of the Disability Rights Convention, people with disabilities have the right to found and maintain a family and to "retain their fertility on an equal basis with others."
- ✓ Article 25 of the Disability Rights Convention states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability hence, governments shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including in the area of sexual and reproductive health and population-based public health programs

Barriers to access proper reproductive health information and services

As defined previously disability results impairment of an individual interacts with barriers in the social environment which prohibits him/her from having equal participation. People with disabilities face numerous barriers in realizing equal opportunities; environmental and access barriers, legal and institutional barriers, and attitudinal barriers which cause social exclusion (DFID, 2000).

Attitudinal barriers have to do with the negative attitudes, beliefs, misconceptions, assumptions myths and stereotypes communities hold about people with disabilities in general. Women with disabilities are often viewed as asexual, incapable of engaging in a sexual relationship, and unable to bear and raise children, which severely limits the information and types of reproductive health services made available to them (CSVR, 2005) . Due to myths and assumptions, persons with disabilities, especially women and girls with disabilities, are not included in SRH information outreach efforts, as these individuals are perceived to have no risk for sexually transmitted infections (STIs), including HIV infection (UNFP, 2007).

People living with disabilities worldwide are far less likely than persons without disabilities to receive and access information on family planning, or access to counseling… the persistent lack of communication from health institutions, organizations and agencies, and also from family members or women community leaders results in women with disabilities being uninformed of safe sex practices (UNFP, 2009). As a result women living with disabilities experience elevated risk for STIs, HIV/AIDS, and unwanted pregnancies (Groce, 2005).

Public campaigns as such are often confusing to individuals with intellectual disabilities who cannot process a surplus of information at one time. Furthermore, Persons with intellectual disabilities are often viewed as not capable of retaining information related to SRH, and thus no efforts are made to teach individuals with intellectual disabilities about sexuality (UNFP, 2009). Furthermore, SRH services are often inaccessible to persons with disabilities for many reasons, including physical barriers, the lack of disability-related clinical services, and stigma and discrimination. In many situations barriers to health services include lack of physical access, including transportation and/or proximity to clinics and, within clinics, lack of ramps, adapted examination tables, and the like (WHO, 2009) .

Theoretical framework: Right based model of disability

Models of disability that have evolved through the years have been used as frameworks to explain and understand disability. The history of disability across the world has been characterized by a progressive development of four models; namely, medical, charity social, and the human rights model. The rights-based model of disability is used as a framework to this paper.

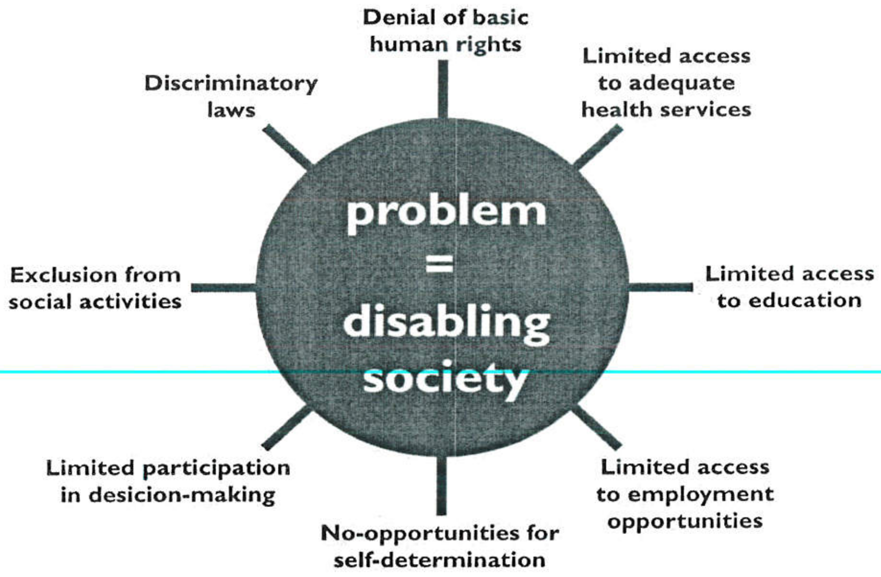

Figure 2: Right based model of disability

Source: Adopted from Handicap International. Making Poverty Reduction Strategy Paper (PRSP) Inclusive.

While discussing disability and human rights approach to development, Albert and Hurst trace the history of human rights approach to development in the 1990s where many multi-lateral and bi-lateral agencies started adopting the approach (Albert and Hurst, 2004).

The human rights approach seeks to ensure that each person is seen as having an equal right to freedom, dignity, non-discrimination and protection from the state against abuse of these rights, together with access to economic, cultural and social rights (Albert and Hurst, 2004). Hence, it is only by empowering all people to be able to make decisions about their lives that states can be able to reduce poverty and achieve the Millennium Development Goals (Albert and Hurst, 2004). As disability describes the barriers faced by people with impairments to achieving equality and justice, and because disabled people are human beings too, it is axiomatic that disability is a human rights issue (Albert and Hurst, 2004, p3).

The rights-based model or the human rights model of disability positions disability as an important dimension of human culture, and it affirms that all human beings irrespective of their disabilities have certain rights which are inalienable. This model builds upon the spirit of the Universal Declaration of Human Rights, 1948, according to which, 'all human beings are born free and equal in rights and dignity' (CUTS, 2003). Furthermore, the model focuses on the fulfillment of human rights, for example the right to equal opportunities and participation in society (Handicap International). Consequently, society has to change to ensure that all people – including people with disabilities – have equal possibilities for participation. It is a fact that persons with disabilities often face a denial of their basic human rights, for example the right to health (physical and psychological) or the right to education and employment. Laws and policies therefore need to ensure that these barriers created by society are removed. The Rights-based

Model states that support in these areas is not a question of humanity or charity, but instead a basic human right that any person can claim (Handicap International).

CHAPTER THREE

Methodology

The research design and methodology

The research used qualitative approach to conduct the study in order to have a deeper understanding of the life experiences of women with intellectual disability. Qualitative approach helps to establish the meaning of the phenomena, which in this case is sexual health problems of women with intellectual disability, from the view of participants (Creswell, 2003). When there is limited research, a qualitative approach is best to understand a concept (Creswell, 2003). Furthermore, qualitative research is important to explore attitudes, behavior and experiences of study participants through methods as like interviews or focus groups (Dowson, 2002). Since the focus of qualitative research is the attitudes, behavior and experiences of participants, fewer people take part in such research (Dowson, 2002).

This research describes sexual health of women with mild and moderate intellectual disability focusing on their knowledge about reproductive health issues and their access to reproductive health information and services. There is limited research on the sexual health problems women with intellectual disability experience. In addition to this, the research focused on obtaining in-depth information from the participants. Hence, qualitative approach was the preferred research method for this study.

Case-study research helps to examines in-depth many features of a few cases over duration of time where the data are usually detailed, varied, and extensive (Krueger and Neuman, 2002). A case study is done with the intent of examining and illustrating the complexity of the issue (Creswell 2007).

Communicating with persons with intellectual disability require extra time, care and attention than persons with sensory or physical disabilities and none-disabled people. While communicating with persons with intellectual disabilities questions have to be reconstructed, repeated and responses probed as often as required to establish clear understanding for all involved.

Hence, with the intension of conducting careful and complete observation of participants and have in-depth information about sexual health of women with intellectual disability, case study method is used.

Multiple data sources should be used in case studies in order to attain an in depth understanding of the cases being studied (Grinnel, 1997). Hence, to further understand the sexual health and cross-check the realities described by women with intellectual disability, family members key informants and staffs of ENAID who have experience working with people with intellectual disability and in areas of reproductive health have participated.

Emphasis was given on the full analysis of sexual lives of selected women with intellectual disability where by in-depth interviews, observation and Focus Group Discussions (FGDs) are the sources of data collection.

Research site

Ethiopian National Association of Intellectual Disabilities (ENAID) formerly known as Ethiopian National Association of Mentally Retarded Children and Youth (ENAMRCY) was established in 1987 E.C by parents of intellectually disabled children. Currently the association has around 2,500 members with branch offices in seven regional states as well Addis Ababa and Dire Dawa. The members in Addis Ababa are approximately 1,000.

Since its establishment, ENAID has been the voice for adults and children with intellectual disabilities by advocating for their right to equality, access to social services and protection. In order to fight discrimination and stigma, increase awareness of community members about intellectual disability and people with intellectual disability, ENAID has been organizing various community sensitization events and discussion.

ENAID has a board structure that evaluates and oversees the plan and execution of activities according to the mission statement of the association. For this purpose, the board meets every three months to evaluate the quarterly activities of the association and provide recommendation. Board members are volunteers who are comprised of experts on the field of disability and parents of members with intellectual impairment. Existing staff of the association includes the general manager, public relations manager, cahier and executive secretary, head and assistant vocational trainers and guards. Except for the head-trainer and guards, all the staffs are female.

The participants of this case study are members of ENAID, which is located at Bole sub city in the area commonly known as *'22 Mazoria'*. Since ENAID operates in all sub-cities of Addis Ababa, members are also from all sub cities. The association has a vocational training center at its main office in '*22 Mazoria*' and at its branch around French Embassy a place commonly known '*Ferensay*'. Hence, the research site is the two centers in '*22 Mazoria*' and '*Ferensay*', where all female members with mild and moderate intellectual disability between the ages of 18-35 are participants of the research. In addition to the participants at the centers, women with mild or moderate intellectual disability from Arada community are included in the study.

Population and Sample

Ethiopian National Association on Intellectual Disability (ENAID) has 2,500 members nationally and 1,000 members in Addis Ababa. Women with mild or moderate intellectual impairment who are members of ENAID are the main targets of the study. This qualitative case study tries to show the challenges women with intellectual disability face in relation to reproductive health by focusing on lives of 10 women.

In collaboration with ENAID staff and key informants, case study participants were selected using the following selection criteria.

Selection Criteria to participate in the research

a) Membership Status: - Members of ENAID who are actively participating at the center in 22 *Mazoria* and *Frenensay* or members whose parents/guardians are active in their community

b) Gender: Female

c) Age: Adolescent women in their reproductive ages who are between the age of 18 and 35

d) Severity level of their disability: Mild or Moderate

The selection of the case study participants was carried out with ENAID staffs. From the two centers, women who have mild or moderate intellectual disability and can communicate better were selected by ENAID. In addition to the 10 women, 4 staffs of ENAID who have been working on intellectual disability for more than 10 years, key informants who are parents/guardians of persons with intellectual disability and are experienced in community sensitization and door-to-door have participated in the interviews. Furthermore, 12 mothers/guardians the association believed to be representative were also included in the study.

Ethical issues considered

This is a qualitative research and the main source of information is women with intellectual disabilities, their families and their association. Hence, participants were fully aware of the objectives the study and their consent were gained through a consent form. The consent form was prepared in a simple and clear language the participants understand. Due to their impairment, in addition to the participants their parents or guardians have also taken part in giving consent.

During the process of the research, caution has been taken no to impose harm or risk to the participants and their families.

Data Collection

Women with moderate and mild intellectual disability were interviewed to get a deeper look at their sexual health and life experiences. Due to the nature of their disability, communication with women with intellectual disability needs to be taken with caution. In order to learn more about the ways of communication and familiarize herself with the study participants, the researcher had arranged an extended observation period at the center for a couple of months (December 2013- February 2014) prior to the research. During this time, the researcher made informal conversations with women and men with disabilities at the center and observed their daily activities (training and production of items) as well as social gathering (Christmas celebration, lunchtime, entertainment day etc). In addition to this, the researcher participated in briefings by ENAID about the activities of the center, the behavior of the members and their socio-economic backgrounds.

As observed during the time spent at the center, there are communication barriers among women with intellectual disability.

- ✓ They understood things when communicated to them in short, simple and direct language
- ✓ It gets difficult for them when one speaks relatively in a faster pace
- ✓ Sometimes they do not respond with words but with a body language
- ✓ They sometimes get upset when they feel people treat them like children or do not respect them

This has required the researcher to be fully alert and attentive at all times. In addition to this, there was sensitivity and preference of eye-to-eye contact among participants. Hence, to make the interview more relaxing and respectful to the participants as well as document their answers well, the researcher avoided taking notes and kept the interviews more casual. The responses of women with mild and moderate intellectual disability were recorded with the consent of the participants and their family/guardian to gather as much information as possible. It took three weeks to finish the interview with all the case study participants and another week to interview ENAID staff, key informants and conduct FGDs with parents.

In order to corroborate the stories, some of the vital information was crosschecked with families or caretakers, key informants who have experience on the issue and experts on intellectual disability have participated. Hence, interviewing, focus group discussion, direct observation and document review is used as well.

Guidelines that help with collection of information were developed. These included interview and FGD guidelines for all the participants and guidelines for observation. To develop these guidelines preliminary information from ENAID staff and key informants about the reproductive health of women with disabilities and literature reviewed were used as an input.

The guidelines were developed in a way to provide information on intellectually disabled women's knowledge and experience about reproductive health organs and functions, sexual intercourse, pregnancy and sexually transmitted infections, sexual abuse and access to reproductive health services. Moreover, the guidelines were developed to identify reproductive health problems of women with intellectual disabilities from the perspective of parents and ENAID staffs.

Methods of data analysis

The data analysis is in accordance with the research questions outlined. The data collected from the interviews and the FGDs were transcribed and grouped first, then summary of this data is presented by thematic area. Following this presentation of data, the findings are analyzed, summarized and discussed in separate sections.

In addition to the interviews and FGDs conducted, direct observation of women with intellectual disabilities at ENAID centers and at their homes was part of the data collection and analysis.

CHAPTER FOUR

Result, analysis and discussion

Analysis of the data is divided in three major sections. The first major section includes results of the interviews of women with mild or moderate intellectual disability from the community and the two locations, namely at ENAID main office around 22 *Mazoria* and ENAID branch office around *Ferensay,* and staffs of ENAID.

Following this, the next section includes results of the key informant interviews conducted with former peer educators of ENAID working on areas of reproductive health. Lastly, the results of Focus Group Discussions (FGDs) held with parents of women with intellectual disability are presented.

Demographic Characteristics of participants

The study describes the reproductive health problems of women with intellectual disability focusing on women of a reproductive age with mild and moderate disability. Participants of the in-depth interview were 10 women with mild or moderate intellectual disability, where nine women are receiving vocational training and engaged in weaving or the production of doormats in the above-mentioned centers and 1 woman was selected from Arada sub city. From the 10 women, eight women (4 with mild and 4 with moderate intellectual disability) were from the center at 22 *Mazoria,* 1 woman with moderate intellectual disability was from the center at *Frensay* and 1 with moderate intellectual disability was selected from the community. Table 1 shows summary of the Socio-demographic information of the case study participants.

Table 2

Socio-demographic information of case study participants

People	Code	Age	Severity level of their disability	Education	Marital status	Living with
Participant 1	20	20	Mild	Primary education	Single	Parents and siblings
Participant 2	21	23	Mild	Primary education	Single	Relatives
Participant 3	23	18	Mild	Primary education	Single	Parents
Participant 4	25	20	Moderate	Primary education	Single	Parents and siblings
Participant 5	26	29	Moderate	Primary education	Single	Parents
Participant 6	27	31	Mild	Primary education	Single	Parents and siblings
Participant 7	28	26	Moderate	Primary education	Single	Parents and siblings
Participant 8	29F	30	Moderate	Primary education	Single	Mother and siblings
Participant 9	31	31	Moderate	Primary education	Single	Siblings
Participant 10	31A	20	Moderate	Primary education	Single	Parents

All women were between the ages of 18-31, are not married and live with either with their parents, siblings or relatives. The participants have not advanced in their formal education that they attended at least to primary level and discontinued when their disability hindered their ability to advance to the next class. Few of them attended schools like *Atse Libnedingle, Belay Zeleke,* and *Adwa Ber* that have special needs classes. All women at the two centers are trained in weaving, production of mops, post cards, doormats and plastic mats for coffee ceremony. Most of the time, they are engaged in weaving and production of doormats. At home, they all have household chores that include cleaning, cooking, washing clothes, gardening and taking care of youngsters.

The first groups of FGD participants are parents and/or guardians who are engaged in savings and small businesses with the help of ENAID. The second groups of parents and/or guardians are parent committee members of women and men with disabilities at Atse Libnedignle School. The parents/guardians are literate and can read and write. Most of them do not have formal jobs and depend on pension and support of their adult children. Among the participants from the savings and small businesses group, two of them have started a small shop that sells home processed food items.

Table 3

Details of FGD participants

Participants	Total number of participants	Number of discussion
Parents from savings and small business group	6	1
Parent committee members at Atse Libnedingle School	6	1

Staffs of ENAID who participated in in-depth interview are the General Manager, the Public Relations Manager and Head and Assistant trainers. All participants were female and have high school and above educational backgrounds. The key informants are parents and/or guardians of members of ENAID who have experience in community sensitization work and door-to-door information service delivery about gender based violence and reproductive health of women with intellectual disabilities.

Data presentation

Brief Description of case study participants

Participant 1:

She is a 20-year-old woman with mild intellectual disability. She lives with her parents and siblings around Addisu Gebeya. She has attended special needs class at Belay Zeleke primary school and then dropped out because she could not advance due to her disability. She can read.

Her father found out about the Association (ENAID) and brought her to the center where she has been taking trainings on weaving. She now weaves on average with 15 other men and women with intellectual disability in the workshop. She manages to travel alone from 22 mazzoria to Addisu Gebeya by using public transport. As she mentioned she uses Anbesa Bus № 80 to come to the center and then go back home with her peers from the center who also use the bus.

Reproductive Health Organs and functions

She is not aware of reproductive organs and their corresponding functions. Although she cannot accurately match each organ with men and women, she knows men and women have different organs and understand the taboo attached to them.

When her first menstrual cycle began, she consulted with her mother and her mother has thought her how to manage it. After a few repeated lessons, she learned how to manage it on her own and she has been ever since.

She does not know exactly why menstrual cycles are present in women of reproductive age; she explains 'it is a gift from God and only women have it'. She has difficulty of remembering things when explained to her orally. (After the interview, I told her about menstrual cycle, sexual intercourse, unwanted pregnancy, STIs and mode of transmission and prevention methods; she recited it back to me afterwards, but not fully though).

Sexual Relationship and Sexually Transmitted infections

She is single, has not been in a relationship. She is a bit shy to talk about boys. She said she does not want to have relationship and no one has approached her and asked her out. She added her mom accompanies her so no one dares to speak to her.

Her knowledge about unwanted pregnancy is limited. She has heard about it and in her understanding it is 'due to a disease and they get pregnant without knowing. She recalls she heard about unwanted pregnancy on television but could not remember all the details. To prevent unwanted pregnancy, she said women have to be careful by not having a boyfriend. For her contraceptive are injections. She did not recall at first that contraceptives can prevent unwanted pregnancy but later added it helps to prevent pregnancy.

She understood what sexual intercourse is. She does not know what condom is. She heard about STI and explained 'on TV they say that the women should be careful not to be vulnerable to STI". She could not name an STI and said "she does not know which disease is an STI"

When probed with questions from different angles, she talks about abstaining and using condom to prevent transmission of HIV.

She explained HIV is a disease that is transmitted through air, sharp things like needles and razor. She does not know how to relate HIV to a STI. To protect herself from HIV, she said her mother keeps her nail clippers and tooth brush separately and only she can use them. HTC she understands is for HIV and that negative means that they are free and positive means they have the disease.

Participant two

She does not know her age because no one has told her when she was born. Family members estimate her age 23 (from her physical development she seems to be in her early twenties). She is originally from rural Dessie area and came to Addis Ababa five years ago and she lives with a relative (her grandmother's niece) near Urael Church. She has not attended school because she left at a young age and came to Menagesha Mariam first to get treatment for her leg. She has a physical disability that she limbs when she walks. In recent years, she enrolled at the Urael Primary School but could not continue because of her disability as she puts it "I could not understand it".

Reproductive health organs and functions

She understands women and men have different reproductive organs and that the organs have functions. She could name the vagina, uterus and penis. Her first period came when she was in Dessie. She has seen her sister and other girls in her neighborhood so she did not tell anyone she just did what they did when their periods came. She prepares re-usable pads from old clothes and use them by washing it after use. She does not exactly understand why women have their periods but thinks only young women have it because older women have stopped giving birth referring to menopause. She has heard of adolescent age she understood that giving birth is one way of the development. She can identify the physical differences between young girls and adolescent women but does not actually know why the difference exists.

Sexual relationship and sexually transmitted infections

She has never been married nor has children. She does not have a boyfriend nor has she ever been in a relationship. She does not want to have a relationship and "since I spend the weekends at home, I don't meet new people". She lived with her grandparents before coming to Addis Ababa, they did not give her away in marriage, and before anything could change, she moved here. She does not know what unwanted pregnancy is but she has heard on media. She does not know what sexual intercourse actually is, she has not heard anyone say it clearly but she has heard a few things. She has heard of abortion from people around her. She heard of contraceptives from friends and on TV are used to prevent pregnancy. She does not know what STIs are nor HIV, she has heard on TV and radio about HIV but she does not know what it is. She has not seen a condom on TV or has not touched or actually seen it.

Participant 3:

She says she is fifteen years old and does not accept her family's claim that she is 18. She lives around former Kebele 24 commonly known as being 'yesomali sefer' due to the large number of Somali people living in the area. She is the only surviving child her parents have. Her oldest sister has passed away. She lives with her parents. She attended school until grade 5 at Addis Raey primary school around her neighborhood. When she could not advance to the next grade, she came to the center to participate in the training. She now works at the workshop weaving cotton to produce a large piece of cotton cloth from which headscarf, tablecloth and cushion covering are made of. Whenever she gets sick, she takes herself to the health stations because her mother does not believe she has any health problems. She added she has a card from

Kebele that enables her to get free services at the health stations so if she feels sick she goes there on her own.

She is too shy that she cannot look people in the eye while she talks. She explains her shyness as lack of frequent interaction because her mother forbids her from socializing with people.

Reproductive organs and their functions

She mentions reproductive organs, but fails to explain their functions. She does not understand and identify the changes that occur during puberty. She recalls the moment her first period came, she fail to the ground while playing with children in her neighborhood and when she noticed blood in her clothes, she assumed it was from the fall. When she told her mother, her mother explained it was her period. Every month she uses a piece of cloth she has made in to pads to control the blood flow. She says her mom does not buy her pads because saying she cannot afford it. She washes the piece of cloth and re-uses them. She manages it on her own. She does not know why only women have menstrual cycles.

Sexual relationship and sexually transmitted infections

She was never in relationship. She explains sexual intercourse as rape and sex with underage children. She then explained pregnancy because of sexual intercourse. She has heard of unwanted pregnancy when a girl in her neighborhood became pregnant. She has heard of women having abortions. For her, contraceptives are injections taken to prevent pregnancy. She said ‘women take them to prevent pregnancy’. She does not know what STI is but when asked about HIV she explained that ‘if a man has HIV and the women does not when they have sex she gets it to’. To prevent HIV she says that ‘everyone should keep their needles, razors and tooth brushes separately’. She learned about HIV at school before she dropped out.

Participant 4:

She is 20 years old lives with her parents and siblings (2 sisters, 3 brothers) around 22 Mazoria. Her disability is moderate and has physical features that can distinguish her as having a disability. She keeps her hair short. She attended primary school at Assay Primary school until grade 7 where her mother also works. She stutters when she talks and some words are hardly understood one has to listen attentively.

Reproductive organs and functions

She cannot clearly identify reproductive organs and their functions. When I asked her if she has her periods yet, she said no because she did not understood. After rephrasing the question and using examples, she understood what I meant and described her menstrual cycle and how she manages it. She buys her own sanitary pad from the nearby shop in her neighborhood and washes after herself on her own. Her mother showed her at first how to put the pads on her panties, how to clean her private area and how to wash her underwear.

Sexual relationship and sexually transmitted infections

She understands the pregnancy and child birth but not the how it happens, nor about intercourse. She walks from home to the center and vice-versa alone. She sometimes faces bullies who called her names and wants her to go to them but she never talks to strangers. Her parents thought her not to talk to strangers or go with them. She does not know what STI is and cannot explain unwanted pregnancy. She takes contraceptives through injections but does not understand what it is and cannot explain why.

Sexual abuse

She has experienced sexual abuse, she described her abuse as " it hurts inside because of what the guy did". According to her she told her parents what 'the guy' has done and they went to the police and he is arrested. She said "let's leave that". The family knows 'The guy' and he came home when she was at home alone watching a movie and then watering the flowers. "My mother is at work, my father goes to work , my sister was at school, my other sister is at work my brothers were not there I was alone". "My brothers hit him and my father yelled at him". "I got sick and I went to the clinic they gave me 'kinin' and 'shirop'.

She was once lost on her way home "I was going home and I got lost 'duryew' grabbed her and he unbuttoned my jeans I screamed but the police did not came". "The police found me later and took me I told him I felt sleepy and I slept on the chair. The police gave me 'kurs' and 'leslasa. I told the 'policeman' the 'durye' who raped me. I gave him my house number", she said reciting their number "and he called home. My father and mother cried. It was long ago."

She gets lost if she travels by bus so she walks. "I know now where my house is I don't get lost if I walk. The problem is bus".

Participant 5:

She says she is 8 years old but she is 29. She lives with her mother and her father around 22. Her sister is married and lives around 'shola'. Her father brings her to the center and takes her home. She did not go to school. Her mother taught her how to write her name in Amharic and she can write her name. Her physical features clearly show her disability. Her head is very small and not proportional to the rest of her body. She has short hair, she cut it short to fight lice and keep it cleaner. Although she does not have a physical disability, she limbs when she walks.

Reproductive organs and their functions

She has not experienced menstrual cycle. She cannot name reproductive organs and their functions.

Sexual relationships and sexually transmitted infections

When asked about sexual intercourse, she said, "I am Christian and I don't go with boys. My mother told me not to walk, eat, or sit with boys because they are 'balege' and they will do 'balege' to me and manipulate me and I will be pregnant. When saying 'balege', she was inferring sex as a taboo and an inappropriate act. She added "I only have girlfriends." She understood when women get pregnant they will have a baby after they are in labor. She does not understand the process of getting pregnant through intercourse because she does not exactly know how intercourse happens.

When talking about HIV she recalls her mother has told her to be careful not to contract it, "Emaye said not to hold needles or razor and not to use anybody's nail clipper. I buy nail clipper from the shop. If I touch it I will be sick. I have to clean and wash myself and have my nails cut not to be sick because of dirt." She does not know what intercourse is or rape, unwanted pregnancy, contraceptive pills.

She works at home and does most of the household chores. She bathes herself on Saturday or Sunday, washes her clothes on Fridays, and cleans the house cooks 'shiro' and 'misir'. "My mother works so when she comes home she bakes 'injera' but sometimes she is tired and when she has pain on her legs, I will boil pasta or macaroni and give it to my father. "For breakfast, I eat bread with tea, "be shay atkishe". I do not go to church I stay home because thieves might come and steal our TV or radio so I watch the house if there is no one. Tomorrow is 'Michael" and it is our turn to prepare a feast next month for Michael so we will bring the 'tsiwa' home.

Participant 6:

She lives in Gerji, with her father, step-mother and 4 step-brothers. She comes to the center by bus or by foot. Her birth mother has passed away. She has a brother who lives with her maternal grandparents. She has attended until grade 6 in Medhanialm School (around St. Paulos Hospital). She dropped out because it became harder to grasp what she has learned and because it became far after they move to Gerji.

Reproductive organs and their functions

She cannot say with accuracy what reproductive organs are or what their function is. She has not heard about the physiological changes during puberty. She manages her menstrual cycle on her own it is not regular. "I use a 'moddes' and piece of cloth to prevent leaking". As she explains it women have menstrual cycles "so that they can have a baby, my peers from the neighborhood told me."

Sexual relationship and sexually transmitted infection

She used to have a boyfriend when she was in school but after their move to Gerji she has stopped seeing him. They used to go to school together. She and her former boyfriend have not engaged in sexual relationship because as she says "I have been taught not to drink with men, I fear they may put something in my drink and make me dizzy and do something bad to me." "Women get raped and pregnant so we have to be careful". "I have never had sex, I have never been raped I have kept my dignity and my pride."

Vaguely describes sexual intercourse and rape. She does not understand the acts but knows rape is forced and both may result in pregnancy or infection. 'Salfelig liaregegn yichilal'is the phrase she uses to describe that if she is not careful and she is too close to a guy he might rape her. She knows there are pills to take to prevent pregnancy she has seen them on TV and a condom can be used to prevent pregnancy as well as HIV. She has not actually seen a condom or pills (Showed her and asked she did not recognize). When asked if she had used contraceptive bills, she said she has never had sex so there was no need to use. She told me about a rape of

Sifen from Shola. *Sifen* (not her real name) is one of the case study participants. “HIV transmits from people to people that is from mothers to children. It is transmitted through needles. scissors, nail clippers and razors. I keep myself protected I don’t have sex.” When further asked she said “women put condoms” but then rephrased it and said “men put it on and then remove afterwards.” She takes contraceptives through injections. What the ‘medicine’ is doing for her is managing the pain of her menstrual cramps, “it helps me not to get sick when my period comes.”

Participant 7:

She lives with her mother, father and her brother who is also has intellectual disability around ‘Chefe Medanialem’. She comes to the center by bus with her father. She often uses the English word ‘no’ in her sentences that she picked up from her mother. Her mother lived in Italy for a while before she was married. She has not attended school and she does not know how old she is. However, she is 26 years old. She was born in Addis Ababa around ‘*Lukanda*’ and the family lived in Eritrea and Tigray before moving back to Addis Ababa.

Reproductive organs and their functions

She does not understand reproductive organs or their functions. She knows about her menstrual cycle and that it comes every month. However, she cannot relate it to her reproductive organs. She buys sanitary pads and manages her periods on her own.

Sexual relationships and sexually transmitted infections

She has never been in a relationship and does not want to have a boyfriend. She does not know what the term sexual intercourse describes. She does not know about contraceptives, she says she does not use. Has no information about HIV. She takes contraceptive injection she thinks it is for her periods. Her family teaches her not to approach men because they will hurt her.

Participant eight

She lives with her mother, sister and brother around 'Ferensay'. She has three brothers and three sisters. She did not attend formal education. She does household chores she washes her clothes, makes coffee, bakes 'injera', cooks and cleans.

Reproductive organs and their functions

She could not explain what reproductive organs and their functions are, but further to the interview, she pointed to her reproductive organ used the proper Amharic meaning and explained about her sexual abuse experience. She does not know the reason menstrual cycle happens and its relationship to pregnancy. She manages her periods on her own. Her mother taught her how to wash herself and her underwear.

Sexual relationship and sexually transmitted infections

She has never been in a relationship and is not currently involved with anyone. She does not have children. Her sister talks to her about sexual intercourse. She understood it to mean that 'she will be ruined' if she befriends men. She could not explain what HIV/AIDS and STI is or how to prevent transmission of STIs.

Sexual abuse

She shared her story of sexual abuse by her grandfather. In her words, this is how she described the abuse;

> "you know my grandfather Demise right? He beat me up and took me. He used me, he ruined me. 'ye bilgna negre adrgognal' three times or so with condom. I told my mother, my sister Melishu was furious. She said I would get pregnant. She also yelled at him and told him to never come to our house". He was arrested he has finished his terms

> and is realized. He climbed on top of me and he did me. My mother told me never to go with him because he is a pervert and he will ruin me" (participant 8).

She has received medical treatment after the rape. At the center, one of the boys training with her tried to take her to the toilet and have sex with her. She said, "I screamed and *Etye Mestawet*-one of the trainers- came and rescued me. He was thrown out of the center."

Participant nine

She is a 31-year-old woman. Her, her older sister, her younger brother and her 10-year-old daughter live around *Shola-Megenagna.* Her younger brother also has moderate intellectual impairment. They both attended the training at the center come to the center and work on weaving and door-mat making. She has attended primary school till she could not pass the 7th grade.

Reproductive organs and their functions

Although not in accurate terms, she can name the respective reproductive organs of men and women. She understands that there is a relationship between these organs and pregnancy but fails to describe it correctly. Her mother, who had passed away a couple of years back, was her caretaker. Her mother had taught her about menstrual cycle how to manage it. The responsibility of taking care of her and the rest of the family has now fallen in to her older sister. She still manages her menstrual cycle and personal hygiene on her own with a close follow up from her sister.

Sexual relationships and sexually transmitted infections

She was never married. She is very active and friendly around her neighborhood. She has male friends but is not currently involved in sexual relationship. She takes contraceptives through injections. It was a decision her sister made to prevent pregnancy. She does not really understand the injections she takes. Her knowledge of HIV/AIDS is like most of the women, limited to the use of sharp objects. Still, she could not relate transmission of HIV/AIDS through infected blood. She also could not explain about STIs.

Sexual abuse

She was raped at the age of 19. As a result, she was pregnant and have given birth to a baby girl. Her daughter is 11 years old and is in 6th grade. She has a tendency to leave the house unnoticed and stay outside with no supervison, which, her sister said contributes to her vulnerability to further abuse within the community.

Participant 10

The last participant of the case study is a 20-year-old women with moderate intellectual disability. She lives with her parents (currently on the process of divorce), twin sisters and her brother in Arada sub city an area commonly known as *Semen Mazegaja.* Unlike the rest of the case study participants, she does not attend the trainees at either center. She attends the special needs education class at Atse Libnedingl School located between *Afincho Ber and Medanialem.* She exhibits a unique character than all of the women. She is enthusiastic and talks freely. Like most of the participants with moderate disability, she has difficulty with words but makes her point clearly by talking slowly. She does household chores and is also active in her school.

Reproductive organs and functions

She explains male and female reproductive organs and their functions more accurately. Although she could not explain it well, she knows menstrual cycle is related to pregnancy. She manages her menstruation on her own.

Sexual relationship and sexually transmitted infections

She had never been in a relationship. She explained sexual intercourse in her own words, which was accurate. She understood the role reproductive organs play in intercourse as well as in the transmission of STIs. When asked about unwanted pregnancy, she could relate sexual intercourse with unwanted pregnancy and the socio-economic effects on women. As she described it unwanted pregnancy often makes young women leave their homes and start living on streets increasing their vulnerability to sexual abuse. She talked about the economic problems single mothers will face and how the cycle of poverty is repeated by their children. As a solution to unwanted pregnancy, she recalls women resort to abortion either by force or through manipulation. She knows that unwanted pregnancy can be prevented by using contraceptives. She does not use any contraceptive but she recognized a sample of tablets shown to her during the interview as birth control bills. She also recognized condom when shown. She tried to elaborated on condom use by recalling a campaign poster she had seen elsewhere.

When asked about what an STI is, she explained it by giving example about rashes and infected wounds, and fluids from either the vagina or penis and how it can be transmitted from a man to a woman or vise-versa through contact of the genitalia. Next, she explained the process of HTC and how couples have to be tested for HIV/AIDS before having sex to know their status.

In addition to this, to prevent the transmission of HIV/AIDS and other STIs she said, 'do not have sex, or if they are a couple they should use a condom'. She explained how condom is put on a penis before sexual intercourse. HIV/AIDS is also transmitted by sharing sharp objects, hence, she added that 'one should avoid using other peoples tooth brushes, razors and needles because if a cut happens the virus can enter in to the blood'.

She said she love watching Television and listening to the radio and these are her source of information. However, her main source of information is her mother who taught her everything she knows about her sexuality and reproductive health.

Sexual Abuse

She has experienced attempted rape one her way to school. As she explained it, a young man grabbed her breasts and her buttocks and asked her to sit on the ground, when she refused he forced her down. She recognized the act as sexual abuse, shouted for help, and broke free and run to her school's compound. She has told her mother about it and they have reported the attempt to the police. There had been follow up from the police but the perpetrator was never arrested. She has also experienced sexual harassment at schools by men with intellectual disability. The parent committee has been informed and decision was passed. In an event of sexual harassment, the committee calls both the children and their parents and passes warning of expulsion from school to students.

Focus group discussion with parents

Moving on to the FGDs held with parents, the following results were gathered. The first discussion was held with a group of mothers engaged in savings and small business scheme. The second FGD participants were parent committee members for woman and men with intellectual disability.

The first five discussion points were about reproductive health issues parents/guardians discuss at home with their daughters/sisters. Points raised included information they give to their daughters/sisters about reproductive organs and their functions, sexual relationship and intercourse and reproductive health issues. In addition to these, parent's sources of the information were also discussed.

According to the discussion, although the severity level of their children is different, parents repeatedly pass information to their children. The inability of their children to retain and process information was discussed to be among the major challenges parents/guardians face. As one parent puts it, "my daughter does not retain what I tell her, she does not differentiate harm from safe so I take her everywhere I go. I often fear she may be lost or worse become sexually abused so I do not let her out of my sight. I tell her repeatedly but she cannot retain and process what I tell her." Another parent from the first FGD said,

> "I have a 23 and 25 years old daughters, I always tell them about their menstrual cycle and teach them how to manage it, about HIV/AIDS and how it is transmitted through needles, razors and sharp objects and about their safety. They listen for a while but they forget it shortly after. It is a struggle because they forget so I have to constantly tell them. I also tell them inform me if you get sick or if something bad happens to you all the time. As much as we want to avoid it they are interested in relationships and boys, it is natural. But I try my best not to leave them alone with boys even with relatives. Because I am scared of what may happen, they do not understand what it means but they want to do what others do"

When discussing the sexuality of women with intellectual disabilities and how parents supervises their children sexual relationships, participants confirmed that they do not let their children have sexual relationships and they do not wish for it to happen in the future. "I never let her socialize with boys because I fear the worst she noticed and asked me why I do not let her. She feels left out it is a struggle but I have to protect my daughter" was the response of one parent. Another participant said "their peers and other young people pressure them in to doing what they do telling them it is ok and good. We as parents try to separate them from boys. I talk to her about the dangers of HIV and sex and try to keep her out of trouble, but it looks as if I am being cruel to her but we all are trying to protect them. It is difficult to balance this".

According to the participants, their children are eager about looking 'normal' and having what their sisters, relatives or women in their neighborhood have. They get excited about weddings and having a family of their own. "They want to be normal so much that they want what they see in others. My daughters love weddings, wedding photos, wedding songs and children so they always say they want a wedding, talk about their wedding dress, sing along when a wedding song comes on and they want a baby."

Although they agreed their daughters are the same and want to become a bride someday, none of the parents want that for them and will not allow them to have relationships. "We do not encourage them about having boyfriends we do the opposite and protect them."

As learned from the two FGDs, parents have only been trained once on reproductive health and in relation to intellectual disability. It was a three days training organized by ENAID in collaboration with Ministry of Health (MOH) and delivered by health professionals. The rest of the information they provide was based on their personal experience and the discussions they share among each other. "We share from our life experience, we have almost forgotten how it was so we need to refresh our knowledge but we do what we can. We tell them what we remember and what we heard from others" (FGD participant).

For most of the parents their daughters becoming pregnant worries them. They are afraid because their children do not understand the seriousness of unwanted pregnancy and the burden of raising children. "My daughter being pregnant is my worst nightmare," says one parent. Most of the parents from the school committee confirm that they take their children to a clinic to have a contraceptive and the injection method is the general choice. "If any of our daughters got pregnant, we will help them abort. We believe it is necessary and the only choice. There is a fear among us that their children may also become like them. We hear not all intellectual disability is hereditary but we do not want them to have go through it like we did" (FGD participant).

The biggest fear for all parents is the possibility that their children might be raped. Some of the parents on the discussion, point out that their children have the tendency to leave the house unnoticed and wonder away. This makes the parents worry that during these times pedophiles may prey on their children and sexually abuse them. One the main reasons parents take their children to clinics to have contraceptive injection is to prevent unwanted pregnancy in the event of rape. "My daughter was raped by a neighbor," said one participant "I do not know if it happened more than once, I am most afraid she may become pregnant so I took her to a clinic and she is injected with a contraceptive to prevent pregnancy. The injection has not settled well with her she has gain a lot of weight she has become overweight."

The rest of the participants also shared a story of a woman with intellectual disability who was raped and became pregnant as a result.

"There is a woman with intellectual disability who is not taken care of well and she slips out of the house often and her aunt said I cannot handle her and go after her every time so she threw her out of the house. She befriends with everyone and she was always vulnerable to abuse. She has told some of the parents she was raped and became pregnant. She still lives on the streets. She is going to be abused again the way things are." (FGD participant)

Another challenge parents mentioned was how women and men with disability sometimes cannot differentiate between an appropriate and socially unacceptable sexual behaviors. They take things to mean literary they may want act out their desires in public without considering whether their actions are appropriate and non-offensive.

"Some intellectually disabled men in the school show sexually deviant behavior. They do not control their sexual urges and often do things without understanding them. They do not understand that expressing sexual desires in public is a taboo or that crossing boundaries of others is wrong. If they see sexual acts on movies, they want to try doing what they saw." (FGD participant)

Another participant added that there were incidents where the men touch female students' breasts or buttocks and try to engage in sexual act. They even try touching the teachers.
"At an event last week there were visitors from abroad and they were dancing to a music when a female student (the one raped by her father) started touching the white woman's breast. The woman told her in Amharic this is not appropriate." (FGD participant)

Major problems identified by parents were vulnerability of women with intellectual disability to sexual abuse, incidences of unwanted pregnancy and inability of women with intellectual disability to process information that will enable them protect themselves.

Research Findings

Based on the above data presented, the following section of this paper presents the findings. The following are sets of reproductive health problems of women with intellectual disabilities identified from the interviews conducted women with mild and moderate intellectual disability, staffs of ENAID and key informants as well as FGDs with parents.

From the above stories of the women, information about the participants' individual experience and their sexual health is collected. Based on the information from the case study participants and the key informants interview, participants knowledge on reproductive health, access to reproductive health information and services as well as reproductive health problems faced by the participants are summarized as follows.

Knowledge of reproductive organs and functions

All, except one of the women who have experienced their menstrual cycles. A couple of them have irregular cycles. All have learned to manage their menstrual cycle on their own. All of them were thought by their mothers on how to manage their cycle and keep themselves clean. Only one of the women interviewed knows the link between menstrual cycle and pregnancy. Neither the process of pregnancy nor the functions of reproductive organs are fully understood by the rest of the participants.

Knowledge of sexual intercourse, pregnancy, unwanted pregnancy, STIs and HIV/AIDS

The term unwanted pregnancy is unfamiliar to all except one. the women are now taking contraceptives through periodic injections. The decision to select the form of contraceptives as well as using the contraceptive was made by parents/guardians. All of the participants do not currently have a sexual relationship. Only one confirmed of having a dated a man. Except one, none of the women understand sexual intercourse and they explain it as something awful men do to women hence, they choose not befriend men. There has not been any attempt from anywhere to teach them or provide appropriate training for them on reproductive organs and their functions, unwanted pregnancy, contraceptives, Sexually Transmitted Infections (STIs) and HIV/AIDS. Except one of the women, none of the women understands what STIs are, how they are transmitted, or how they can protect themselves from the infections. For most whenever there is a mention of HIV what they immediately say is that it is a disease transmitted through using other people's needles or razors or toothbrush. They do not understand it further as one of the STIs.

For all of them, whatever information they receive on reproductive health matters, the information came from their mothers. They have not participated in campaigns or awareness raising events that targeted women with intellectual disability. The never had any information materials they can read and learn about their sexuality.

Knowledge and use of condoms and contraceptives

Although they do not quite understand how it works and what it does, they have heard of birth control methods and condoms from the promotional advertisements aired on television or radio. At one time or another they have all gone to the clinic to have services related to reproductive health but none of them could recollect and describe the services. However, from the 10 women interviewed four of them have been regularly going to reproductive health clinics with their mothers/guardians and take contraceptive through injection. In addition to this, parents/guardians from the FGDs have confirmed that the do take their daughters/sisters to a reproductive health clinic to have a regular contraceptive injection. They added that their daughters/sisters will not understand about prevention of pregnancy and contraceptives hence discussing the it with them would not matter. When shown samples of condoms and birth control pills, none except one could identify what they were. In additions to this, when pictures of other methods of contraceptives were shown, women who had injections relate to the picture of a woman having an injection and say that they have done that to. But they could not recognize any of the other methods of contraceptives in the pictures.

Vulnerability to sexual abuse

Family and community's lack of awareness about sexuality of women with intellectual disability is another challenge for women with intellectual disability. There is a general belief that they are not sexually active, have no sexual desire and do not understand it. This belief in addition to limiting their access to reproductive information and services, it is also among the reasons they are prone to sexual abuse.

There is vulnerability to sexual abuse due to various factors. Their disability and the perception others have on their disability is among the reasons women with intellectual disability are vulnerable to sexual abuse. Often, family only focuses on the occurrence of unwanted pregnancy in the event of rape and considers the solution to this problem is giving them contraceptives. There is also the fear by family members is they start to use contraceptives they will automatically start having sex or it is a sign of having sex and that becomes shameful for them.

From the case study participants, four of them have experienced rape and one has experienced attempted rape and sexual harassment.

Access to reproductive health information and services

None of the women interviewed had participated in a campaign or awareness raising event that particularly targets their nature of disability. They do not have access to brochures or pamphlets prepared for persons with intellectual disability about reproductive health. Those who have gone to reproductive health clinics were not fully informed of the services. Due to the communication barrier, they did not receive any training or information on reproductive health.

The interview held with staffs of ENAID, key informant reviled that, woman with disability in general, and women with intellectual disability in particular do not have equal access to information and services related to reproductive health. They are often vulnerable to sexual abuse through either force or manipulation more than other women are. When non-disabled women face unwanted pregnancy, whatever choice they make will be based on their informed consent. Other women make the decision based on the information made available to them, however women with intellectual disability do not have the ‘luxury’ of choice. If the need arises for them to get reproductive health services, parents take the role and take them to the services and they get the services whether they understand it or not. Furthermore, there is barrier of communication when they try to access services. Information is not available for women with intellectual disability in a way the understood things. Like everyone else, women with intellectual disability have the biological urges that come with adolescent age. Hence, information and services should be made available to them in their own capacity. Institutions providing reproductive health services are not accessible to them and their officers are not aware about intellectual disability so there is a problem of awareness.

Women with intellectual disability have as much right as non-disabled women to equally access information and services; have the right to be involved in deciding the kind of contraceptives they use as well as to choose if they want to have children. Women with intellectual disability have zero access to information and lack the awareness. They have not exercised their right fully because there is not information and accessible service. Awareness activities on media is does not address the specific needs of persons with disabilities and does not consider their audiences are also women with disabilities.

There is lack of awareness about intellectual disability among service providers that hindered intellectually disabled women's access to reproductive health services

Those working on reproductive health do not include disability in their actions hence, leave out women with intellectual disability as their targets.

Problems at home, school, community and health services

Women with intellectual disability face problems at family, school, community and health services due to lack of awareness about their disability and their sexuality. In the family, women with intellectual disability are not given the opportunity to access basic information about sexual intercourse, STIs and contraceptives. They are not given the opportunity to decide whether they want to use contraceptives or not. The focus is more on unwanted pregnancy than STIs and HIV. The family fears that they might be raped and get pregnant so they focus on preventing unwanted pregnancy. At the community the belief that women with intellectual disability do not have sexual desire or are unwanted has become left many to believe that women with intellectual disability are virgins or are free of HIV. In addition to this, women with intellectual disabilities cannot give consent and are easily manipulated in to doing things they do not understand. This has made them more vulnerable to sexual abuse. At schools, gender clubs and reproductive health clubs do not include women with intellectual disability. Many of the women are sexual abused within the community and at schools.

According to ENAID, most parents prefer to go to Family Guidance Association of Ethiopia (FGAE) because it is relatively disability friendly and it offers better reproductive health services. Hence, other health services have also need to include disability in their programming. During the discussions with key informants, the major reproductive health challenged raised was sexual abuse of women with intellectual disability and the apparent vulnerability to STIs as a result. One of the key informants shared the story of Adey who was raped by her father as follows:

> “Adey lives around *Shiro Meda* , her moth er has passed away and she lives with her father. She told other mothers of women with intellectual disability at the school that she was raped by her father and did not tell anyone. She was pregnant at one time but the child died during birth. From our previous community work, we heard from neighbors he drinks a lot and sexually abuses her but nobody has dared to report the ‘crime’. They also say that he has been using her to satisfy his sexual desires. She still lives at home and has come back to school” (key informant).

Discussion

This part of the paper further elaborates on sexuality of women with intellectual disability and their access to reproductive health information and services. Sexuality is a reality to men and women of all kinds and each individual should be given the chance to live it fully. The following text is a view of one of the participants of the case study on sexuality, love, relationship and marriage.

> "The man and the woman will talk on the phone. The woman will ask him to go out on a date. She wants to meet him in a café in Piassa-she is a bit classy. He will say yes, he will send her SMS message and they will chat. The woman stands in front of a mirror and fix her hair and makeup, put on lipstick, wears her beautiful dress cloth and then put on her high heels. She will wear her black or brown top. He will bring her red roses- a flower of love-He will surprise her. He buys her nice cloths and she will give him gifts. They will drink wine in a candle light. He will play a song on the tape recorder, grabs her by the waist and they dance. On the day of their wedding, he will wear his black suit and she will wear her *'Velo'*-white wedding gown. They share vows and exchange rings. They will have their wedding pictures taken at 'Wondweson photo studio'. The wedding is at Ghion Hotel everyone will drink whisky there. They will live as a married couple and will have children" (Participant 10).

What is written above describes how like any other woman, a woman with intellectual disability is captivated by love and relationships. For all the women in the case study this is a dream that is far from their grasp. They are not given the opportunity to express their womanhood; they lack knowledge about their own sexuality; they do not have access to information about sex, pregnancy, sexually transmitted infections, contraceptives and are vulnerable to sexual health problems. Furthermore, they are most vulnerable to sexual abuse, which in turn increases their risk of vulnerability to unwanted pregnancy, HIV/AIDS and other forms of STIs.

Assumptions about their capacity to learn and act accordingly have denied women with intellectual disability from acquiring vital information and making informed decisions. From the case study participants, who have received vocational training and are producing items like headscarves, coffee table covers and doormats, one can see women with intellectual disabilities are capable of learning. In addition to their work at the center, they all perform household chores at their house, which they carry out according to the instructions passed on from their parents. What is common to all the participants is that their families and others around them have assumed that the women do not understand about reproductive health. Families fear about abuse, exploitation, pregnancy and sexually transmitted infections have made them shelter the women so much that they are denied the right to grow into adults who are able and allowed to have relationships that provide companionship, conversation, trust, love and an appreciation of who they are. Relationships do not always lead to sexual intercourse and the positive aspects of sexuality and affection are natural, healthy expressions of our humanity, whether or not we have an intellectual disability. The mothers/guardians in the study have confirmed that their anxiety that their daughters may face unwanted pregnancy had forced them to rely on constant contraceptive injections. Those participants who are taking contraceptive injections do not understand its use and they have not given their full consent to it. The focus on unwanted pregnancy only does not solve the problem of sexual abuse and exploitation as well as vulnerability to HIV/AIDS and other STIs.

Reproductive health education and awareness raising campaigns suited for women with intellectual disability are not available and this has widened the information gap further. The case study participant quoted above, has relatively better knowledge and information about her own sexuality, unwanted pregnancy, contraceptives, HIV/AIDS, condom, STIs and sexual abuse. The significant difference she has from the rest of the participants rest in the constant discussion she has about the issues with her family, especially her mother. In addition to her knowledge on the matter, she exhibits a more firm and confident character than the rest. She is very active and outspoken both home and school. As gathered from her family members, she was not always like that. Most of her life she never left home, she could not take care of herself and her mother did everything for her. Things improved after the training her mother had at ENAID. She began to teach her how to take care of herself, do household chores, enrolled her to special needs class and interact with her more. In doing things repeatedly and taught constantly, she has changed over the years.

Information tailored to the level of understanding of women with intellectual disability can help in improving sexual health problems they face due to lack of knowledge. In addition to access to reproductive health information, participants also lack access to reproductive health services that is considerate to their disability. Attitudinal, communication and physical barriers that exist in health facilities are the challenges expressed by key informants and parents in relation to access to reproductive health services.

CHAPTER 5

Conclusion and implication for social work

Understanding the functions of the body particularly reproductive organs, the socially acceptable ways of expressing ones sexuality and the basic reproductive health rights is the first step in having a fulfilling sexual life. For women with intellectual disability, the first problem identified is the inaccessibility of reproductive health information. This inaccessibility limited the knowledge of women with intellectual disabilities concerning issues such as their reproductive organs and their functions, their sexuality, pregnancy, unwanted pregnancy, STIs, modes of transmission of STIs, prevention methods for unwanted pregnancy and socially acceptable expression of sexuality.

The main information source for the women are parents who themselves are not properly trained about reproductive health of women with intellectual disability. Parents often omit information they assume are irrelevant due to the nature of their children's impairment or encourage inappropriate sexual behavior.

Educational and promotional information targeting women and men of reproductive age have not been inclusive of women with intellectual disability. This gap in information was evident in the women's lack of awareness and knowledge on the issues. None except one of the women who participated in the study has knowledge of STIs and could only associate HIV/AIDS to cuts and wound. They could not recognize a condom or the different types of birth control pills when presented to them nor understand their functions well. They do not have the basic knowledge that will help them protect themselves from unwanted pregnancy and STIs.

Another major challenge identified is the vulnerability of women with intellectual disability to sexual abuse. Families' fear of unwanted pregnancy following sexual abuse or manipulation has led many of them to put women with disabilities on continuous contraceptives. This is a necessary respond to prevent unwanted pregnancy, however it is done without the full consent and understanding of the women. In relation to this, the psychosocial and health complication that result from sexual abuse are not given as much attention as unwanted pregnancy. This is contributing to factors that make women with intellectual disability vulnerable to STIs and HIV/AIDS.

Lack of accessible reproductive health services is one major problem. Health services are not often disability inclusive that there are attitudinal, physical, institutional and communication barriers. These barriers are also present for women with intellectual disabilities. Women with intellectual disabilities lack access to disability inclusive HTC services and family planning services.

Women and men with intellectual disabilities have unmet psychosocial and economic needs that require the attention of social development agents and policy makers. They are marginalized parts of the community who have long been neglected by social and economic service providers. The family, especially mothers have direct impact on the development and wellbeing of persons with intellectual disability in general and women with intellectual disabilities in particular. Hence, programmatic areas focusing on strengthening the family and developing their capacity should be developed to address the needs of women and men with disability.

Women with intellectual disability have the right to access reproductive health information and services tailored to their specific disability needs. Therefore, outreach services, awareness raising activities and service delivery systems should be inclusive of and considerate to their disability.

As it is a profession promoting social change, well-being and empowerment of marginalized groups, working towards equal access to reproductive health services and the promotion of safe sexual health for women with intellectual disability has to be a concern for social work. Human rights and social justice are fundamental to social work hence, working to ensure the respect of reproductive health rights of women with intellectual disability and helping them have dignified sexual life is significant to social work profession.

REFERENCE

American Association on Intellectual and Developmental Disabilities. Definition of Intellectual Disability retrieved from *http://aaidd.org/intellectual-disability/definition#.U1-jJKxZ4lc*

Ann Elwan.(1999).Poverty and Disability: A survey of the Literature

Betterhealth Channel. (2014). Fact Sheet on Intellectual disability and sexuality retrieved fromhttp://www.betterhealth.vic.gov.au/bhcv2/bhcpdf.nsf/ByPDF/Intellectual_disability_and_sexuality/$File/Intellectual_disability_and_sexuality.pdf

Bill Albert and Rachel Hurst.(2004).Disability and a human rights approach to development

CUTS International.(2011).Disability-Human rights based models vs the social, medical and charity model

Catherin Dawson (2007). Practical research method: A user friendly guide to mastering research

Centre for the Study of Violence and Reconciliation (CSVR). (2005). On the margins: Violence against women with disabilities. Retrieved from http://www.csvr.org.za

Cheung N. (2013).Defining intellectual disability and establishing standard of proof: A suggestion for national Model standard. Health Matrix 23(1)

Gillian Eastgate. (2008). Sexual health for people with intellectual disability

Handicap International, SHIA, HSO.(2009). A guidance paper for an inclusive local development policy: background information tools for action at local level support material.

Handicap International.Handbook on "Making Poverty Reduction Strategy Paper (PRSP) Inclusive". Retrieved from http://www.making-prsp-inclusive.org/en/6-disability/61-what-is-disability/611-the-four-models.html

Handicap International.(2009). Policy paper. Inclusive local development: how to implement a disability approach at local level

Human Rights Watch. (2010). Human Rights for Women and Children with Disabilities

ICPD(2013).Policy Recommendations beyond2014 International Conference on Human Rights.The Sexual and Reproductive Rights of Women and Girls with Disabilities

International Federation of Social Workers. (2012). Definition of Social Work retrieved from http://ifsw.org/policies/definition-of-social-work

International Network of Women with Disabilities. (2011). Violence Against Women with Disabilities

International Planned Parenthood Federation.(2003).Charter on Sexual and Reproductive Health Rights

Japan International Cooperation Agency.(2002).Country Profile on Disability Federal Democratic Republic of Ethiopia

Jill Astbury and Fareen Walji. (2013).Triple Jeopardy: Gender-based violence and human rights violations experienced by women with disabilities in Cambodia

John W. Creswell. (2003).Qualitative, quantitative and mixed method approaches

John W. Creswell. (2007).Qualitative inquiry & research design: choosing among five Approaches

Katherine Guernsey, Marco Nicoli, Alberto Ninio. (2006). Making Inclusion Operational. Legal and Institutional Resources for World Bank Staff on the Inclusion of Disability Issues in Investments Projects retrieved from http://siteresources.worldbank.org/INTLAWJUSTICE/Resources/LDWP1_Disability.pdf

Marc J. Tassé.(2013). DSM-5 AND ICD-11: Possible Implications For Intellectual Disability And Autism Spectrum Disorder.

Mobility International USA.(2001). Gender And Disability: A Survey of Inter-Action Member Agencies. Findings And Recommendations on Inclusion of Women and Men with Disabilities in International Development Programs

National Commission persons with Disability.(2007).Rights, not Charity

Nora Ellen Groce.(2005).HIV/AIDS and individuals with disability

Richard M. Grinnel(1997). Social Work research and evaluation: quantitative and qualitative approaches

Sexual Health & Family Planning Australia.(2013).Improving Sexual and Reproductive Health of People with disabilities

Tammy Reynolds, C.E. Zupanick,. & Mark Dombeck. Intellectual Disability and Severity Codes retrieved from http://sevencounties.org/poc/view_doc.php?type=doc&id=10351&cn=208

Teaching Sex Ed for Youth with Intellectual Disabilities retrieved from http://www.sexualityandu.ca/teachers/teaching-sex-ed-for-youth-with-intellectual-disabilities

Tirussew Teferra.(2005).Disability in Ethiopia: Issues, Insights and Implications

United Nations.(2007).Convention on the Rights of Persons with Disabilities retrieved from www.un.org/disabilities/convention/signature.shtml

United Nations.(2013).List of signatory states retrieved from www.un.org/disabilities/countries.asp?nvaid=17&pid-166

United Nations Population Fund (UNFPA).(2009).A situational Analysis of the Sexual and Reproductive health of women with disabilities.

United Nations Population Fund (UNFPA).(2007). Emerging issues: Sexual and reproductive health of persons with disabilities.

W. Lawrence Neuman and Larry W. Kreuger.(2002). Social work research methods: Qualitative and quantitative

Women With Disabilities Australia.(2011). Assessing the situation of women with disabilities in Australia: A human rights approach

World Health Organization.(2009).Promoting sexual and reproductive health for persons with disabilities

World Health Organization and The World Bank .(2011). World Report on Disability.

APPENDICES

Appendix I

Interview participants consent form

As a requirement for MA degree in Social Work, I am conducting a research on Intellectually Disabled Women's Access to Reproductive Health Services. The interview includes discussion about reproductive health of women with intellectual disabilities and the challenges they face based on personal experiences.

I will use the information provided by the participant only for the purpose of this research. To protect the participants' privacy, the identity of the participant will not be made official and it will be kept anonymous.

This consent form is prepared to help the participant make an informed decision to participate in the research. Hence, the participant has understood about the research and have been fully informed and have agreed to be interviewed and participate in the research by providing information to the researcher.

Therefore, both the researcher and the participant has signed this consent form and have agreed to proceed with the interview.

Name of the researcher	Date	Signature
______________	__________________	__________________
Name of the participant	Date	Signature
__________________	__________________	____________________

Appendix II

Interview guide for women with intellectual disability

I. Personal Information

1. Code
2. Age
3. Place of Residence
4. Currently living with
5. Educational background
6. Marital status

II. Reproductive health organs and functions

7. What other changes do occur when girls reach adolescent age?
8. What are reproductive organs in women and men and what is their function?
9. What is a menstrual cycle?
10. Why do women have menstrual cycles?
11. When did you see your first period?
12. How did you know what to do?
13. Have you have any training on how to manage your period?
14. Where did you learn that?

III. Sexual intercourse, pregnancy and Sexually transmitted infections

15. Have you ever had a boyfriend?
16. What is sexual intercourse?
17. Who thought you about sexual intercourse?
18. Have you ever had sexual intercourse with your boyfriend or any other man?

19. Have you ever been pregnant? How, When?
20. Do you know what unwanted pregnancy is? How?
21. Have you ever had an abortion? Why?
22. What are contraceptives?
23. Have you ever taken contraceptives? Why?
24. What kind of contraceptives have you took? Why?
25. What is STI?
26. What is HIV/AIDS?
27. How are HIV/AIDS and other STIs are transmitted?
28. What are the methods of preventing transmission of HIV/AIDS and STIs
29. Do you know how to protect yourself from STIs?
30. What is a condom?
31. Have you ever seen a condom?
32. What is the use? How is it used?

IV. Sexual abuse

33. Have you ever experienced sexual abuse?
34. Who was the perpetrator?
35. Where did it happen?
36. Can you explain how it happened?
37. Who have you told?
38. Did It happen again?

V. Access to reproductive health information and services

39. Where do you learn about sexual intercourse, pregnancy, contraceptives, condom, HIV/AIDS and STIs?

40. Have you ever participated in awareness raising about unwanted pregnancy HIV/AIDS and STIs?

41. Were there any campaigns that reached you about unwanted pregnancy HIV/AIDS and STIs?

42. Have you ever gone to Reproductive Health clinic?

43. What kind of service did you get at the clinic?

44. What problems did you face when you went to clinic?

45. Whom did you go with?

46. How did they communicate with you at the clinic?

47. How were you treated?

48. Have you ever had legal protection for your sexual abuse?

49. Have you ever had psychosocial support after the sexual abuse?

50. What challenges have you faced due to your sexuality?
    - home
    - school
    - community
    - health stations

51. What would you want to do different about your sexuality?

Appendix III

Interview guide for families/guardians of women with intellectual disability

I. Personal Information

1. Age
2. Marital Status
3. No of Children
    - 3.1. No of children with disability
    - 3.2. Type of disability
4. Educational background
5. Source of income

II. Reproductive Health Issues

6. What reproductive health issues do you discuss with your daughter?
7. What have you thought her about reproductive health?
8. Where did you learn the information you gave her?
9. Why have not you thought her about reproductive health?
10. Do you talk to her about boys, relationship and sexual intercourse? What do you tell her?
11. Is she allowed to date?
12. How do you supervise her sexual relationship?
13. How do you feel if she gets pregnant?
14. Have you ever dealt with unwanted pregnancy with her? how did you deal with it?
15. Do you help her get contraceptives? How?
16. Does she understand why she takes them?

17. Do you think she has the right to decide on her own? Why?
18. Do you let her exercise these rights? Why?
19. What reproductive health challenges have she faced?
20. What challenges have you faced due to your daughters sexuality?
    - Home
    - Community
    - School
    - Health stations
21. Have you ever access reproductive health services for your daughter at a health station/clinic? Can you describe the process? What challenges were there?
22. What do you think will be best for her reproductive health?

Appendix IV

Interview guide for key informants and experts working with women with intellectual disability

I. Personal Information

1. Educational background
2. Professional background
3. Position
4. How long have you worked in areas of disability? How many of it on intellectual disability
5. Do you have any disability? What is your disability?
6. Do any of your family members have a disability? What is their disability?

II. Reproductive Health

7. What are the reproductive health needs of women with intellectual disabilities?
8. How are these needs addressed by your organization?
9. What are reproductive rights of women with intellectual disabilities?
10. Do you think women with intellectual disabilities have exercised their rights? How? Why?
11. What challenges do women with intellectual disabilities face with regard to
    - their sexuality
    - reproductive health
    - access to information and services

at

- home

- community
- school
- health stations/clinic

12. Are there any local/national/international laws or policy that promote equal access to reproductive health information and services for women with intellectual disabilities? Can you give me names?
13. How does your association/organization help promote and implement these policies?
14. What is the role of parents/guardians/care takers in reproductive health of women with intellectual disabilities?
15. How do parents/guardians/care takers affect reproductive health of women with intellectual disabilities?
16. Are reproductive health information and services accessible to women with intellectual disabilities?
17. What kind improvement needs to be made to make reproductive health information and services accessible to women with intellectual disability?
18. How can these improvements be made?
19. Who are the stakeholders and what are their roles?
20. What do you want to add about reproductive health of women with intellectual disabilities?

Declaration

y confirm that this study titled “Women with Intellectual Disability ve Health Information: A Case Study”, is my original work, has not er university and that all materials used are duly acknowledged.

Kebede Signature Date: 16/12/14

(Phd) Signature Date: