GIFTED COMMUNITY CENTRE

SILENT CONVERSATIONS BASELINE SURVEY REPORT

ENHANCING HIV/SRH KNOWLEDGE OF WOMEN WITH INVISIBLE DISABILITIES

Figure 1: Focus Group Discussion with caregivers at GCC office

BASELINE SURVEY OF WOMEN AND GIRLS WITH INVISIBLE DISABILITIES IN KIBERA

October-November 2019

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We further thank the county and sub county health divisions, the local government and other stakeholders we interacted with during this exercise.

LIST OF ACRONYMS

AIDS- Acquired Immunodeficiency Syndrome

DPO- Disabled People Organizations

GCC- Gifted Community Centre

HIV- Human Immunodeficiency Virus

NCPWD- National Council for Persons with Disabilities

NGO- Non-Governmental Organizations

PWDs- Persons with disabilities

SRH- Sexual and Reproductive Health

UN CRPD- United Nations Convention for the Rights of Persons with Disabilities

UNFPA -United Nations Population Fund

WRA- Women of Reproductive aged 15-49 years

VI- Visually Impaired

HI- Hearing Impaired

WHO –World Health Organization

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EXECUTIVE SUMMARY

Women of reproductive age including those with disabilities ought to have an opportunity and avenue where they can express their needs for them to have both rights and responsibilities in promoting their own health and development[1].

Studies in Sub-Saharan Africa have shown that adolescents and youth are more vulnerable to HIV infection, therefore posing a great danger of high incidences of HIV transmission and high prevalence rates in cases where there is little knowledge and awareness on HIV and AIDS. Our work in Kibera continues to expose us to the harsh realities of inequities driving the health seeking behavior of girls and women with disabilities. Persons with disabilities (PWDs) in need of sexual and reproductive health (SRH) services continue to face discrimination while seeking services from the providers for fear of their information not treated as confidential.

Against this background, the gaps that exist in the knowledge and capacity of SRH services among PWDs necessitated GCC to commission a baseline survey to understand and explore possible ways that can ensure demand and supply of SRH services are met. This survey was also important in laying down the groundwork for activities and interventions that would help achieve the goals and objectives of the "silent conversations project for enhancing HIV/SRH knowledge for women with disabilities". Guided by the overarching goal of creating an enabling environment for access and the right to comprehensive SRH and family planning services, the methodology for the survey was sensitive to uncovering data that would help us lay out and understand this goal. A summary of the key findings is summarized as follows:

On knowledge and awareness of various issues on maternal, newborn and child health (MNCH), only 59% of women and girls with invisible disabilities in Kibera were knowledgeable. Specifically:

- The study found that the knowledge levels are at average in all components tested, including SRH information (73.7%), HIV/AIDS (86.2%), and contraception (60%).
- There are diverse sources of information in Kibera. Health facilities as the main; acting as an opportunity to the population on all aspects of SRH under study.
- The actual contraceptive uptake among women and girls with invisible disabilities is lower given health facilities in Kibera are reporting increased cases of unwanted pregnancies.
- On issues of sexuality, respondents indicated they are free to discuss with health service providers, followed by parents and peers.
- On HIV/AIDS, despite the high knowledge levels and the high response in terms of services sought, the respondent feel they are stigmatized, discouraging them to seek such services in future.

On service accessibility, 55% of the respondents reported that the services were accessible. Similarly, 53% of the respondents reported that the available services are adequate to their needs while 52% felt that the services were affordable and acceptable. Specifically:

- Accessibility was viewed by the respondents as services being informative, good, friendly and efficient

[1] Ministry of Health, Republic of Kenya. National Reproductive Health Policy. Government of Kenya. (2007) Pg. 14

- Affordability was viewed through the availability of a sign language interpreter. Furthermore, health facilities were profiled by the respondents as expensive and lacking sign language interpretation services among other reasons.
- A major gap exists on service provision, particularly on how to address the disability issues and how in terms of infrastructure, facilities are not accessible
- Fifty-nine percent (59%) of respondents had sought MNCH services. The common services sought in MNCH include antenatal care (41%), delivery (31%), postnatal care and cervical cancer screening (25%).

On different disabilities in relation to access of services:

- Persons with hearing impairment are the most marginalized and neglected largely through communication at both community and health facilities
- Persons with visual impairment and those with mental health conditions also report marginalization and discrimination especially when seeking services
- Generally, PWDs face communication, infrastructural and attitudinal barriers that must be addressed for them to enjoy equal opportunities. This demands an integrated approach on how this project should be operationalized. The approach will focus on decision makers, service providers, PWDs through their organized units (DPOs) and the community (leaders, religion, parents and caregivers).

In conclusion, the results of this survey recommend that:

- There is need for increased awareness and education to PWDs, the community members, caregivers and family members on SRH and rights, as well as disability
- There is need to engage like-minded organizations, DPOs and government institutions like the National Council for person with Disabilities (NCPWD) to advocate for mainstreaming of the services to be inclusive
- There is need for a multi-pronged and diverse approaches to influence institutions, communities, persons with disabilities and even policy makers
- Opportunities to strengthen SRH service provision exist, including legislation, global development agenda (SDG), the health service provider expressing need to understand disability and how to assist them, and the like-minded organizations already working to strengthen these components in mainstream services.

1.0: INTRODUCTION

1.1: Introduction and Project Background

The World Health Organization (WHO) estimates that 10% of the population has a disability[2]. The United Nations estimates that this percentage may be higher, and 25 percent of the world's population may be living with a disability. The Convention on the Rights of Persons with Disabilities (CRPD) defines persons with disabilities as "*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*"[3]. In 2006, the Convention on the Rights of Persons with Disabilities (CRPD) was adopted and subsequently entered into force in 2008. Many countries have since signed and ratified it, including Kenya. The CRPD in Articles 23 and 25, references to universal access to sexual and reproductive health and rights.

Kenya National Survey for Persons with Disabilities in 2007 established that 4.6% of Kenyans experience some form of disability and only 16% of women with disabilities aged 12-49 years use some form of family planning. According to the Kenya Population Household Census in 2009, it was reported that 3.5 percent of the population reported some form of disability. Visual 24.9% and hearing (14.1%) are the most prevalent forms of disability. Other domains included Speech (12.2%), Physical (25.3%), mental 10.2% and self-care (5.8%) [4].

Persons with disabilities are generally vulnerable and face a number of compounding risks in relation to their health and physical form against violence, exploitation from labor, attitudinal discrimination, maltreatment and accessibility (communication and infrastructure). The female population with disabilities is more marginalized than their counterparts including the risk for accessing health services.

Health infrastructure of most developing countries neglects the needs of persons with disabilities, thus the situation for women with disabilities is dire in this context[4]. Access to sexual and reproductive health services (SRH) for women with disabilities is not only a human right, but it will also help the international community to realize the Sustainable Development Goals on Health and Gender Equality, which later translates to the rest of SDG targets, with special focus on SDG 3, on ensuring healthy lives and promoting well-being for all at all ages. The ratification of the CRPD and the promulgation of the Constitution of Kenya, is now the responsibility of the government of Kenya with support of the international community, private sector and well-wishers to address the sexual and reproductive health (SRH) needs of women with disabilities.

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[2] World Health Organization/United Nations Population Fund. (2009). Promoting sexual and reproductive health for persons with disabilities. Retrieved from http://www.who.int/reproductivehealth/publications/general/9789241598682/en/

[3]

[4] Presentation of Venus M. Ilagan, Secretary General of RI, at UNFPA's expert Meeting on the right to sexual and reproductive health services Tudor Hotel, New York 8-9 October 2009.

4. https://unstats.un.org/unsd/demographic-social/meetings/2016/kampala--disability-measurement-and-statistics/Session%206/KENYA.pdf

1.2: About Gifted Community Centre

Gifted Community Centre (GCC) is a registered, independent, disability and development youth led (community-based) organization formed for and by youth with disabilities in Nairobi, Kenya. GCC seeks to empower youth and other persons with disabilities residing within the informal settlements of Nairobi, particularly Kibera, and to an extent reach out to college/university youth with disabilities. We mentor, educate, inform, empower, and advocate on and for the rights of persons with disabilities in pursuit for independence, decent living, and full utilization of untapped potential of youth with disabilities.

Our vision is to shape the future of every youth with disability where every one of them has a dignified life and secure income. GCC mission is to become the leading organization where every youth with disability has the opportunity to achieve their full potential, and fully participate in all the aspects of life. The following objectives guide us:

(a) To support persons with disabilities into sustainable livelihoods through capacity building training, business start-ups, and direct employment
(b) To improve the skills, knowledge, and experiences of youth with disabilities through multi-faceted approaches
(c) To improve the literacy levels and rates of children and adults with disabilities
(d) To assist and support individual talents, and enhance personal employability programmes
(e) To advocate and create awareness about the rights of persons with disabilities

1.3 Kibera

Kibera Sub County is one of the 17 Sub counties in Nairobi City County, Kenya. It is located in the South West part of Nairobi County. It borders Langata and Dagoretti Sub counties. Kibera is the second largest slum in Kenya with an estimated population of 250,000 projected from 2019 census[5].

Kibera is composed of villages namely Silanga, Laini saba, makina, mashimoni, Soweto East, Kianda, Gatwekera, Kisumu Ndogo, Kambi Muru among others. Kibera covers an area of 225ha and 6.6km from Nairobi City Center. The top five diseases for over five years as at March 2019 were Upper respiratory diseases, Diarrhoea, pneumonia, Urinary tract infections & hypertension. There are 37 health facilities both private and public (KHIS, 2019). The main economic activity in the area is informal Jua kali sector activities, casual labourers and small business.

1.4 Project Description

As a response to the many social and health related ills that continue to befall women and girls with disabilities in Kibera, GCC is running a project whose aim is to improve women with disabilities knowledge and capacity to access sexual and reproductive health (SRH) and family planning services. The Project dubbed ***'silent conversations: Enhancing HIV and SRH knowledge for Women with Disabilities***' is envisaged to create an enabling environment for access and the right to comprehensive SRH and family planning services. The project set of interventions will ultimately contribute to the decline in unintended pregnancies as well as support

[5] http://worldpopulationreview.com/countries/kenya-population/

the prevention of HIV/AIDS efforts. The project will deploy the simplest ways and localized mediums to reach out to women with invisible disabilities both infected, uninfected and affected, caregivers and health service providers. The target group will be empowered, sensitized and information transcribed in disability friendly formats in the targeted informal settlement. In addition, the community members will be well informed to respond to cases of Prevention of Mother to Child Transmission (PMTCT) and involve persons with disabilities in the HIV/SRH activities.

With regard to the project, GCC commissioned a baseline survey to understand the capacities, knowledge, challenges and opportunities to better engage the target population with a bias to **women with invisible disabilities**. *An "invisible," "non-visible," "hidden," "non-apparent," or "unseen" disability is any physical, mental, or emotional impairment that goes largely unnoticed. An invisible disability can include, but is not limited to cognitive impairment and brain injury; the autism spectrum; chronic illnesses like multiple sclerosis, chronic fatigue, chronic pain, and fibromyalgia, hard of hearing; blindness and/or low vision; anxiety, depression, Post Traumatic Stress Disorder, and many more*. It is understood the body is always changing, so disability and chronic illness may be unstable or periodic throughout one's life.

This study focused on invisible disabilities that included hard of hearing/hearing impairment, speech impairment, low vision/visual impairment, intellectual disabilities, epilepsy and invisible multiple disabilities.

2.0: METHODOLOGY

2.1: Survey Objectives

The purpose of the baseline study was to generate adequate and quality baseline information (quantitative and qualitative) against a set of indicators as benchmarks.

2.2 Data Collection Tools

Data was collected using questionnaires, key informant interview guide (KII) and the focus group discussion (FGD) guide. The tools in particular sought to identify the level of knowledge, their capacities, needs and opportunities for persons with disabilities to access sexual and reproductive health services. The tools included beneficiary demographic information, access to sexual and reproductive health services, sexuality and contraception, and maternal and neonatal health. A focus group discussion guide targeting caregivers focused on access to SRH for PWDs, challenges and opportunities for PWDs in their access to SRH services at service delivery points, at household and in communities was employed. Key informant interviews guide included general information on the facility, services offered and if PWDs access such services as well what can be enhanced to better mainstream the services.

Data collection tools reflected on the local context. The tools were pretested and feedback from the different stakeholders was used to strengthen the tools. (See Appendix 1)

An appropriate methodology was adopted to answer the survey objectives. The survey design followed a logical sequence to ensure a credible and orderly assessment process as outlined in the terms of reference from inception activities, design, fieldwork data collection, and synthesis phases culminating in the final output assessment report. A data validation mechanism was used to verify data sources through triangulation of responses with literature reviewed, as well as regular consultations.

Qualitative assessment focused on documenting the expectations, challenges and opportunities that GCC can enhance in collaboration with the government and like-minded partners on SRH service provision.

2.3 Geographical Scope of the Assignment

The survey was conducted in Kibera sub-county.

Figure 2: Map of Kibera area coverage

2.4 Population of Study

The survey targeted both primary and secondary stakeholders including girls and women of reproductive age 15-49 years with disabilities, health workers in both private and government facilities, and caregivers.

2.5 Sampling Design

Both probability and purposive sampling techniques were used to select the key members of the study population.

a) **Purposive Sampling**: Purposive sampling technique was used in selecting participants (women and girls), and key informant interviewees. Women of reproductive age 15-49 years were selected because of their role in the project, especially on SRH matters. Their engagement informed the strengths, needs, opportunities and any other systemic gaps for consideration by the project. The health workers were targeted as key informants because of their role in SRH service provision and the influence they have on the health system. Due consideration was given for key informants in terms of experience, exposure and knowledge in matters related to the project. Focus group discussion participants' selections were also purposive to caregivers because they provide health care service provision. Acquiring information from them would equally inform on the gaps in the health system, community level and household level. Then this would inform the project on the different interventions and approaches that encompasses these aspects.

b) **Targeted sampling**- This was informed by the community health volunteers (CHVs) and identified mobilizers. Having worked in Kibera and having mapped out a set of households in their daily routines, CHVs were instrumental in identifying women and girls with invisible disabilities. The mobilizers selected had a lot of experience in community work and have worked with people with disabilities, including disabled people organizations (DPOs); therefore, making it easier to identify where the target group could be found. Considering

persons with invisible disabilities as generally categorised, are fewer and widely dispersed. A sample size of sixty (60) PWDs were identified and by census approach, all were targeted. The community health volunteers who were the mobilizers helped in identifying the women of reproductive age (WRA) 15-49 years. Besides being a WRA, other inclusion criteria was one who had the selected invisible disability, lived in Kibera for the past six months and consented. For the focus group discussions, twelve (12) caregivers were identified from the eleven villages in Kibera. Key informants (8) included health service providers including community health workers. The CHVs who were assigned to the sampled community units had in their course of public health interacted with these women and children. The additional benefit was their prior experience and the friendships that they had created.

2.6 Data Collection Methods

To meet the research objectives, the study used both quantitative and qualitative techniques to collect data from both primary and secondary sources. The data was collected using the following methods:

a) **Desk/Literature Review:** This method was instrumental in building up the context of SRH from a disability and human right perspective and particularly instrumental at formative and analysis stages of the study. It involved reviewing of secondary information from various sources including UNFPA, WHO and CRPD documents, the Constitution of Kenya, Disability Act, and various national organizations' reports. It entailed a critical analysis of the key documents related to the assignment to address the assessment objective and scope of the assignment. The search was conducted on google scholar, WHOLIS (World Health Organization Library Database) and PubMed Central besides organizational and national documents review. The search terms used were disability, invisible disability, sexual and reproductive health, SRH rights and access to SRH services.

b) **Key Informant Interviews (KIIs):** This method was used to obtain primary information from a cross section of purposively selected key informants with relevant knowledge, experience and insight into the subject matter. (See Appendix 1)

c) **Structured Interviews/Questionnaire**: This method was used to collect data from program beneficiaries. It involved face to face interviews with selected beneficiaries using a pre-coded questionnaire in their households. The significance of pre-coding the questionnaire was to facilitate the administration of the questionnaire, including forestalling any misinterpretation of questions or recording of irrelevant information. (See Appendix 1)

d) **Focus Group Discussion (FGDs):** The focus group discussions mainly targeted caregivers of girls and women with disability. Focus group discussion guidelines were developed to guide the discussions. (See Appendix 1)

2.7 Units of Analysis

The unit of analysis were the SRH caregivers, the health service providers and the household members and specifically women of reproductive age 15-49 years with invisible disabilities.

2.8 Quality Control

To ensure maximum quality control, the technical team ensured close monitoring, supportive supervision and accountability by every member of the team. The enumerator and mobilizer teams were trained and briefed on the selection of respondents, data collection tools, and ethical aspects of the assignment (See Appendix 2). During and at the end of the fieldwork, the supervisors received and verified the data collected by each enumerator in terms of completeness, accuracy and consistency. The verified questionnaires and field notes were then handed over for data entry, collation and analysis. This process was meant to ensure that there was no to little omissions and that quality would be assured at every stage of data management process.

2.9 Training on Survey

A one-day comprehensive training was conducted to enumerators, characterized by role-plays and illustrations. The training was to ensure that the data collected would be reliable.

The training focused on:

- Project description and survey purpose
- General interviewing techniques
- How to go about key informant interviews and focus group discussions
- Role of interviewer
- Questionnaire review

The key area was FGD and Key Informant Interviews. The training process involved lecture approach with handouts, and a number of role-plays among the trainees. This enhanced their understanding and confidence in administering the questions. The training objective was to prepare the trainees of what to expect during the actual interviews; and it largely touched on

etiquette, ethics, how to ask and listen and how to engage the interviewee without loss of interest, or appearing as though bombarded.

2.10 Pilot

The trainees conducted a pilot study a day after training to at least one interviewee each, who did not form part of the eventual sample population. The piloted questions were to ensure coherence, identify any points of divergence, clarity issues, inconsistency and eventually the sense making of the asks to the objective of the survey.

Any points that raised concern were addressed during the review with the enumerators, and a clearer questionnaire adopted for the actual data collection. The pilot was important as it assisted in the verification of tools, as relevant to the agenda of the survey.

2.11 Data Collection Process

Data collection involved both mobilizers and enumerators. The mobilizer's roles were to identify participants that met the criteria of enrolment in the study. This involved linkages to disabled people organizations and or networks of persons with disabilities. The mobilizers including CHVs were of relevance as they assisted the enumerators identify and interview respondents in good time.

The enumerators engaged identified interviewee for between 30minutes to one (1) hour per household. The process was effective, despite challenges of distances between identified interviewees. This was addressed through better planning and appreciation of the dynamics of Kibera. The household data collection process took four days, the FGD one day and the key informant interviews took another day. Sign language interpreters were used for the participants who had hearing impairment.

Table 1: Data collection groups

Data Collection Tool	Target Group	Period
Household questionnaire	60 women with disabilities of reproductive age	4 days
Key informant interviews	8 service providers	2 days
Focus group discussion	12 care givers of persons with disability	1 day

2.12 Data Entry and Data Processing

Data was shared with the survey team on a daily basis and was entered into excel sheet by an assistant data entry. This process took six days, and the seventh day involved data cleaning, to fix errors and inconsistencies, and coding. The data was then analyzed using both excel and SPSS for the household data, as qualitative data was analyzed thematically.

2.13 Limitations and Challenges on the Survey Process

Despite the success of the whole process, some challenges existed that necessitated adaptive methodologies particularly coping mechanisms among enumerators. Key challenges included; the vast area of coverage and the need to visit households to conduct the interviews. The challenging timings between interviewers and interviewees and some interviews had to be rescheduled for the weekend. Kibera is generally vast, and identification of respondents through mobilizers took some time, which also affected the interviews initial schedule.

2.14 Ethical Considerations

The consent forms including (photo and video) were developed and used for administration of the questionnaire and focus group discussion. The assent forms were also used for key informant interviews. The interviewees were free to opt out of the interview at any time or refuse to be interviewed from the outset. For the target group aged below 18 years, caregivers gave the consent on their behalf. The personal identifiers including assigned codes and names were not used in the report to ensure confidentiality and data protection.

3.0 FINDINGS AND DISCUSSIONS

3.1: Section 1: Bio-Data

3.1.1: Demographic Characteristics

In summary, all respondents from the interviewed households were female interviews, had an average age of 31years with a majority aged between 15 and 34 years (72%). This is the youth bracket in Kenya, and among most marginalized in accessing basic SRH services. With regard to marital status, majority of the respondents were single by 68.3%, married 25%, and separated, divorced and widowed were at 1.7% respectively.

The study sought to understand as well the education level of respondents, as their education also has direct and indirect influence on their economic status, access to information and services as well as advocating for their rights. Majority of the respondents had finished primary level education (70%), those cleared secondary level were at (15%), and the tertiary level at 11.7%. as observed, and none at (3.3%); This number decreases upon the next transition of education level. This indicates that there are generally low literacy levels among the target group.

On employment, majority of respondents are employed (62.1%), casual laborers are at 24.1%. Self-employed and volunteers are at 5.2% respectively and the unemployed at 3.4%. The employment status influences income levels, which also reflect on access to basic services.

Table 2: Social demographic characteristics of mapped women with invisible disabilities

Category	**Percent (n)**
Age	**% (n)**
15-19	17% (10)
20-24	28% (17)
25-29	12% (7)
30-34	15% (9)
35-49	28% (17)
Marital status	**% (n)**
Single	70% (41)
Married	25% (15)
Separated	2% (1)
Divorced	2% (1)
Widowed	2% (1)
Education level	**% (n)**
Primary	70% (42)
Secondary	15% (9)
Tertiary	12% (7)
No education	3% (2)
Employment status	**% (n)**
Employed	62% (36)
Casual laborer	24% (14)

Self employed	5% (3)
Volunteer	5% (3)
Unemployed	3% (2)
Gender	**% (n)**
Female	100% (60)

3.1.2: Type of disability and household income

The respondents' type of disabilities included: respondents with hearing impairment (27.6%), visual impairment (19%), mental health (17.2%), intellectual disabilities (6.9%), epileptic (12.1%), multiple disabilities (13.8%) and cerebral palsy and autism at (1.7%) respectively.

Table 3: Type of disability

Type of Disability	Percent (n)
Hearing Impaired	29% (17)
Visually Impaired	19% (11)
Mental health	17% (10)
Epileptic	12% (7)
Intellectual	7% (4)
Autistic	2% (1)
Cerebral Palsy	2% (1)
Multiple	14% (8)

Household Income

The study sought to understand the household income levels per month for the respondents. The household income is the aggregate earnings of all household members; estimated as monthly income multiplied by 12 months. (Monthly income was arrived at by adding the income from all persons contributing to the income in the same household). This excluded house transfers whether in kind or in cash, but focused on what respondents earned from employment, self-employment, financial investment and rent. The study used $1.90 or Kes. 190 as the standard (poverty line threshold) for income per day, therefore anyone earning below this per day or 5,700/= per month was living below the poverty. The limitation of this method was that it was a self-declaration approach, and therefore there could be recall bias in some instances and sometimes-wrong estimates shared.

Table 4: Monthly household income

Income range	Percent (n)
Less than 5,000	33% (7)
Between 5,001 and 10,000	33% (7)
Between 10,001 and 15,000	24% (5)
Between 15,001 and 20,000	5% (1)
Above 20,000	5% (1)

The results show that 33.3% of the respondents are living below the poverty line and 66.7% are above. According to a study by Amelie and Sophie (2011, pp 9)[6], the income per person is calculated by dividing the income per household by the number of individuals; for Kibera it is 3,977 Kenyan Shillings (Kes) per person per month (39 USD); on average according to KNBS (2015/16) household integrated survey report, an average household has 4 people. Therefore, respondents indicate a below average earning.

Section 2: Knowledge and Awareness on Sexual Reproductive Health

The study sought to understand among respondents (women and girls with disabilities) their knowledge and awareness on various components under sexual and reproductive health. This specific objective was meant to help understand their capacities and how the project will plan to address gaps identified.

3.2.1: Availability of Sexual Reproductive Health services

This section sought to understand the extent to which services are available whenever they are needed. It therefore looked at their availability and their access. To an extent the study also endeavored to find out what kind of information persons with disabilities sought in these health facilities.

The study sought to understand if the respondents are aware of avenues where they can share, deliberate, be informed and discuss issues of sexual and reproductive health. In response, 84.6% are aware of the avenues and they can physically visit them. However, 15.4% indicated they did not know. The responses clearly indicate the good level of awareness on the avenues of services available, and what facilities provide them.

This question was also to identify linkages between availability and access to health facilities, and the corresponding was to identify particular hospitals that provided SRH services, or rather, respondents have visited or know of. The health facilities listed were categorized based on whether they are government or private facilities and the levels. Most respondents indicated Kibera South facility at 21.6% followed by Shofco at 18.9%; CDC and Dream Girl had 8.1% respectively.

Table 5: Health facilities visited

Government Owned Facilities	**Proportion of women with invisible disabilities who have made contact with the facility at least once**
Kenyatta National Referral Hospital	3%
Mbagathi Hospital	3%
Kibera South Health Center	3%
Kibera Amref Health Center	3%
Kibera Division Office Health Center	3%
Lindi Health Center	3%
Makina Clinic Health Center	3%
Private Owned Facilities	

[6] Amélie Desgroppes, Sophie Taupin. Kibera: The Biggest Slum in Africa?. Les Cahiers de l'Afrique de l'Est, 2011, 44, pp.23-34. halshs-00751833

Shofco Clinic	19%
CDC Clinic	8%
Dream Girl Center	8%
Senye Clinic	5%
Joseph Kangethe Clinic	3%
Eden Queen Clinic	3%
Ushirika Clinic	3%
Tabitha Clinic	3%

Respondents indicated that on average they are likely to access private facilities over government facilities, factors contributing to this included: distances to the facilities, accessibility, affordability and acceptability. As shown above, private facilities were mentioned more than government facilities **with exception of Kibera South health center.**

One of the key informants had this to say about government, level 2 facilities:

"Services are provided indiscriminately unless caregivers of persons with disabilities cannot express fully the needs of the patient. Indeed, we receive many patients and queues may not favor persons with disabilities, hence opting for private facilities".

However, during a focus group discussion, a caregiver indicated that, "*health workers ignore PWDs in queues, and sometimes solicit for money to assist them".* This contradiction indicates there is need to mainstream the services to be inclusive to avoid divisive perspectives and improve general service provision as well as empower the marginalized.

Section 3: Sexual Reproductive Health Information Access

The study further wanted to understand if respondents have ever received information on SRH services. The study-defined access in relation to services and information as the ability for the users to receive such when there is need, to the quality that is acceptable, affordable and available.

3.3.1: Access to SRH Information

The study sought to understand if respondents could access the SRH information and services.

Majority at 74% indicated they had received information on SRH. The SRH information implied is the information persons with disabilities wanted or asked for, and they were given as per their needs. In addition, considering various means or channels for accessing such, PWDs accessing relevant information for their health was also received as accessible SRH information.

As indicated below, the study also inquired if respondents have ever paid a visit to a health facility and what services or information was being sought. The responses indicate 63.8% had visited a facility, as 36.2% had not. The services sought included maternal health (2.6%), relationships (5.1%), treatment (5.1%), HIV/AIDS (35.9%), and contraception (51.3%).

Table 6: Services sought

Service	Percent (n)
Contraception	51% (20)
HIV/AIDS	36% (14)
Relationships	5% (2)
Treatment	5% (2)
Maternal health	3% (1)

Contraception services includes accessing right information on the services, their benefits or risks, modern birth control methods, procedures or related education and counselling. HIV/AIDS services and information includes testing, counselling, medication and control measures for further transmission. Maternal health services and information include information on antenatal care, prevention of infections, underweight or related, post-natal care, breastfeeding, vaccination, and information and services for infants and under-five children. Relationships, this was understood as services on counselling, courtship and managing expectations between partners. Treatment includes actual methods or measures used to manage illness or disease.

The respondents expressed an understanding of these services being available at the different facilities, whether government or private facilities. However, some felt some of these services are paid for and therefore not accessible to everyone, especially on modern birth control methods.

3.3.2: Source of SRH Information

The study further sought to find out where they had received the information from. Most respondents indicated they get SRH information from health facilities (70.7%); followed by schools (9.8%), facilitators and media (7.3%) respectively and parent at (4.9%). Regarding facilitators, GCC was mentioned as one source, followed by Plan international, and Action Network for the Disabled and disabled people organizations (DPOs). Media sources included TV, Radio and to a little extent social media. The little extent of social media access could indicate low penetration of smart phones because of economic status or closely linked to untargeted usage of smart phones for SRH information.

Table 7: Source of SRH Information:

Source	Percent (n)
Health facility	71% (29)
School	10% (4)
Facilitators	7% (3)
Media	7% (3)
Parent or guardian	5% (2)

3.3.3: Preference source of SRH Information

The study further wanted to understand if they had preference of where to receive the information. Respondents indicated they would prefer information from health facility (73.8%), followed by facilitators (9.5%), school and media at (7.1%) respectively. Parents were preferred at 2.4% only.

Table 8: Preference source of SRH Information:

Preferred source	Percent (n)
Health facility	74% (31)
Facilitators	10% (4)
Media	7% (3)
School	7% (3)
Parents	2% (1)

The study further wanted to understand why the respondents had the above preferences. Their responses are summarized below:

Table 9: Preference reasons

Preferred Source	Reason
Parents	Better understanding Trustworthy not to share information with others They are closer Can teach as you grow
Health workers	They are patient with people They are trustworthy and non-judgmental They have a duty that they committed to uphold Privacy and confidentiality assured Explains better to the youth Easy to communicate with Health workers are highly skilled Gives the right information Have comprehensive information Hospitals are well equipped
Teachers	Can explain better and they trust them
Facilitators	They explain better and are more exposed
Media	Easy to get information Watching programs on TV that provides sign language Sometimes newspapers assist them

As indicated above, key concerns include privacy and confidentiality, as well as availability and provision of right information by qualified personnel. Therefore, the government can aim to mainstream the services so they can reach to intended groups without a feel of discrimination.

3.3.4: Health facility visit

The study sought to know if respondents had visited a health facility to seek for services of SRH. 63.8% had visited to seek services.

3.3.5: Type of services sought by respondents

The study sought to find out the types of services sought at the health facilities; contraception (52.8%), HIV/AIDS (23.3%), treatment and relationship counselling (3.3%) respectively.

Table 10: Services sought by respondents:

Services received	Percent (n)
Contraception	53% (19)
HIV/AIDS	25% (9)
Maternal health	17% (6)
Epilepsy diagnosis	3% (1)
Treatment	3% (1)

Table 11: Type of disability and services frequency

Disability	Services				
	Contraception	Epilepsy diagnosis	HIV/AIDS	Maternal health	Treatment
Epileptic	2	1	-	1	1
Hearing Impaired	5	-	5	2	-
Intellectual	2	-	-	-	-
Mental health	4	-	-	-	-
Multiple	-	-	2	1	-
Visually Impaired	5	-	2	2	-
Frequency Total	**18**	**1**	**9**	**6**	**1**
Percent Total	**51**	**3**	**26**	**17**	**3**

Contraception and HIV/AIDS services are the most sought after in health facilities; particularly by persons with hearing impairment and followed by those with visual impairment.

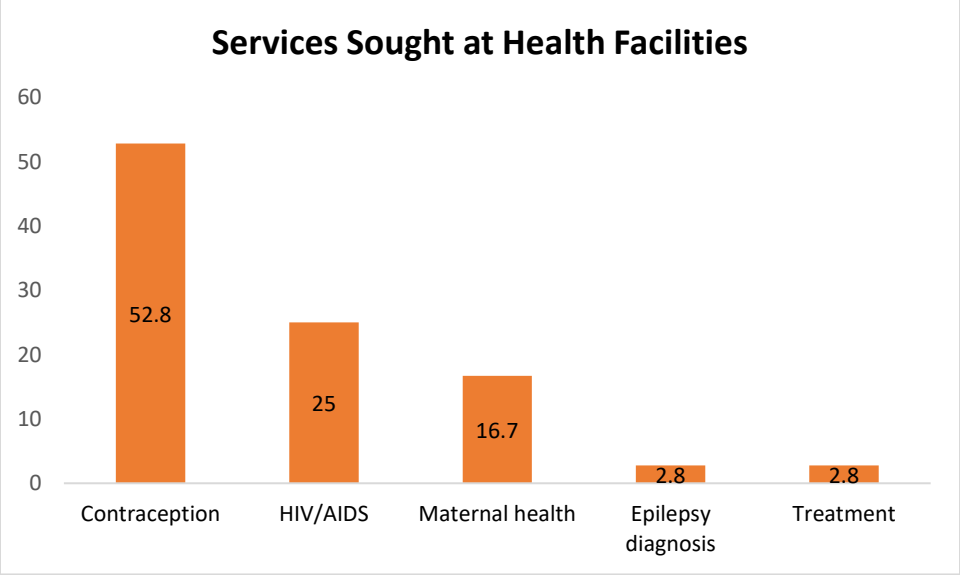

Figure 3: Services sought at health facilities

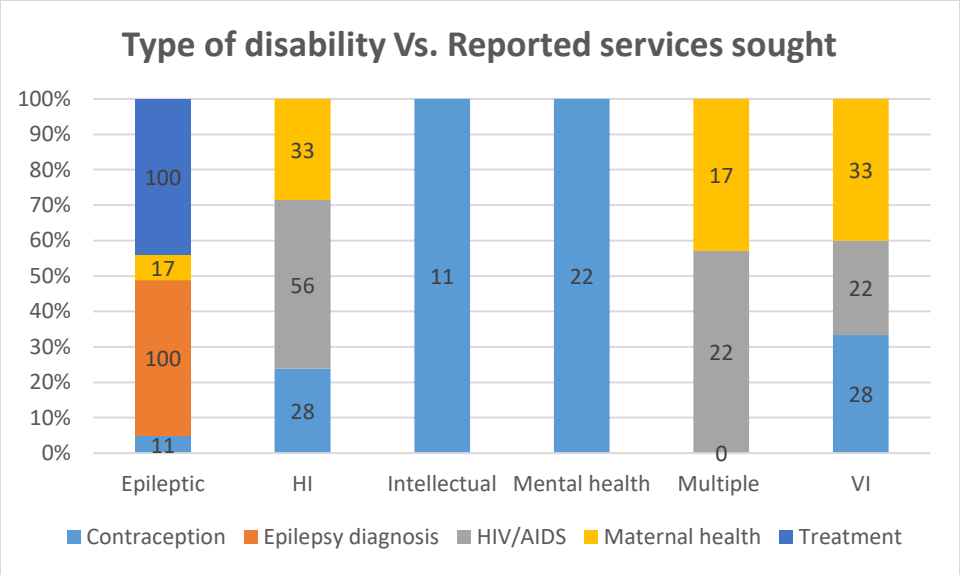

Figure 4: Type of disability vs. services sought

The figure above shows type of disabilities and the services they reported to have sought. Persons with epilepsy sought contraception services at (11%), epilepsy diagnosis (100%), Maternal health (17%) and treatment (100%). This shows that all persons with epilepsy sought treatment and epilepsy diagnosis.

For hearing impairment, 28% of respondents sought contraception services, 56% sought HIV/AIDS services and 33% sought maternal health. For intellectual disabilities and mental health conditions, they sought contraception services at 11% and 22% respectively. Those with multiple disabilities sought HIV/AIDS services at (22%) and maternal health services at (17%). Those with visual impairment, 28% sought contraception, 22% sought HIV/AIDS and 33% sought maternal health.

Section 4: Service Accessibility

According to World Health Organization[7], universal health coverage is attained when people obtain the health services they need and benefit from financial risk protection. Service accessibility is therefore the availability of good health services within reasonable reach of those who need them in a number of service organizations like appointment processes, opening and closing hours/days to allow people acquire necessary services. Affordability is the measure of people's ability to pay for services without financial strain. This includes their transport to and from, and the time taken. Services acceptability is the willingness of people to seek services. This encompasses influential aspects like culture, religion, language, gender and ethnicity.

The study therefore sought to identify if respondent seeking services found these services accessible, available, adequate, acceptable and affordable. Majority at 61.7% indicated the services as available while 35% did not. On adequacy, 53.3% felt the services were adequate, as 10% did not find the services adequate. Regarding affordability, 51.7% reported the services as affordable, 10% did not consider services affordable. The 36.7% reported as not applicable, in the context of never seeking the services.

[7] David B,. Justine H,. & Ties B,. https://www.who.int/bulletin/volume/91/8/13-125450/en/

On accessibility, 55% considered the services as accessible, as 6.7% did not consider so. A key informant interview from Kibera D.O clinic indicated that they do not receive a large number of PWDs, because the facility is not accessible for wheelchair users.

"Not many because of the access especially for wheelchair users".

On acceptability, 51.7% indicated to find the services acceptable while 10% did not indicate so. Most indicated that the services even though acceptable lacked privacy particularly for persons with hearing impairment and mental disabilities. A key informant from Family Health Options indicated that,

"The only challenge is when they are accompanied by a caregiver, and they are seeking services on HIV/AIDs for instance, it becomes difficult to keep information confidential".

-This can be improved through enhanced advocacy by disabled people organizations together with like-minded organizations and the national bodies like National Council of Persons with Disabilities (NCPWD).

Table 12: Accessibility factors observed

	Availability		**Adequacy**		**Affordability**		**Accessibility**		**Acceptability**	
	Frequency	%	Frequency	%	Frequency	%	Frequency	%	Frequency	%
Yes	37	63.8	32.0	84.2	31.0	83.8	33.0	89.2	31.0	83.8
No	21	36.2	6.0	15.8	6.0	16.2	4.0	10.8	6.0	16.2
Total	**58**	**100**	**38**	**100**	**37**	**100**	**37**	**100**	**37**	**100**

The survey intended to seek what respondents' opinions on to why or why not they had sought the services at the health facilities. Some of their views included:

Why for:

- Services were good and informative, health worker friendly and used little time (n=10)

- The facility organizes for a translator as they know me (have been served for a long time at this facility) (n=1)
- The services are free, making them affordable, one could spend on drugs only, which often is missing in the drug stores (n=9)
- They treat me well whenever I visit the hospital (n=1)

Why not:

- It is difficult to go to hospital because I do not have the money (n=1)
- Services offered are expensive, and no Sign Language Interpretation (n=5)

This reflects on the quality of services offered. Most of the respondents felt it is good service, friendly health workers, rich information and infrastructural and communication accessibility; with few facilities mentioned as expensive and inaccessible. Generally, as observed, there is good relationship, trust between health facilities and persons with disabilities seeking services.

The study sought to understand the purpose of health facility visits; of which majority indicated was to seek treatment (81.6%), to seek information (8.2%), to collect ARVs (4.1%), HIV testing and medicine at (2%) respectively.

Besides treatment as the key reason for visiting health facilities, a good number also seek health information. This reflects on goodwill between health facilities to educate the community it is serving, and the good relationship and trust built between the facilities and PWDs.

Table 13: Number of times SRH services sought by respondents:

	Frequency	Percent
1-5	49	81.7
10-15	11	18.3
Total	**60**	**100.0**

Table 14: Type of health facility accessed by respondents during their last visit:

	Frequency	Percent
Government facility	22	45.8
Private facility	26	54.2
Total	**48**	**100**

The survey also sought to know how many times the respondents have sought services in the past one year. Majority have sought services between one and five times in the year at 81.7% and 18.3% reporting 10-15 times.

The survey wanted to also find out the choice of facilities to visit and what informed such choices. As such, the table 15 above shows 36.7% (n=22) visited government facilities and 43.3% (n=26) visited private facilities.

The respondents stated their reasons for their choices as follows:

- Proximity and convenience (23.5%)
- Cost affordability (29.4%)
- Efficiency, equipped and organization (11.8%)
- Parent influencing choices (5.9%)
- Availability of support services like sign language interpretation (5.9%)
- Only available option (8.8%)
- Referral (5.9%)
- Specific services offered e.g. HIV/AIDS counselling (8.8%)

Table 15: Table indicating reasons for choice of facility per disability type:

Reason and Disability Type	**Government**	**Private facility**
	Frequency	**Frequency**
Autistic		1
It is close, they understand my condition and we have a good relationship where she can be treated and I pay later (mother)		1
Cerebral Palsy		1
Proximity to home and affordability		1
Epileptic	2	5
Had good reputation		1
Her documents are there		1
It is the only one she knows	1	
Proximity to home		1
Hearing Impairment	5	9
Convenient		1
Fast service		1
For counselling and HIV testing		1
Free medication/services	1	
Government hospitals have no SLI		1
Parent chose for her	1	
Proximity to home		2

She started her treatment there		1
The aunt chose it since she was the one paying		1
The parent chose for her	1	
They have a SLI	1	
Intellectual	2	
The services are free	1	
Mental health	4	3
Free medication/services	1	
Free services	1	
She is intellectually disabled and has been attending Mbagathi since 2015. She has been staying in the house under the mother's care. She does not go to the hospital		
They provide good services		1
Multiple	3	1
Kenyatta Hospital	1	
Parent chose for her	1	
She used to go to Mbagathi but is now at home because it has become expensive	1	
There is a fee of 200		1
Visually Impaired	5	4
Better equipped		1
For treatment	1	
Free medication/services	2	
Free services	1	1
It was after working hours in government hospitals		1
Proximity to home since she could not see		1
Referral	1	
Efficient and organized	1	
Grand Total	**22**	**24**

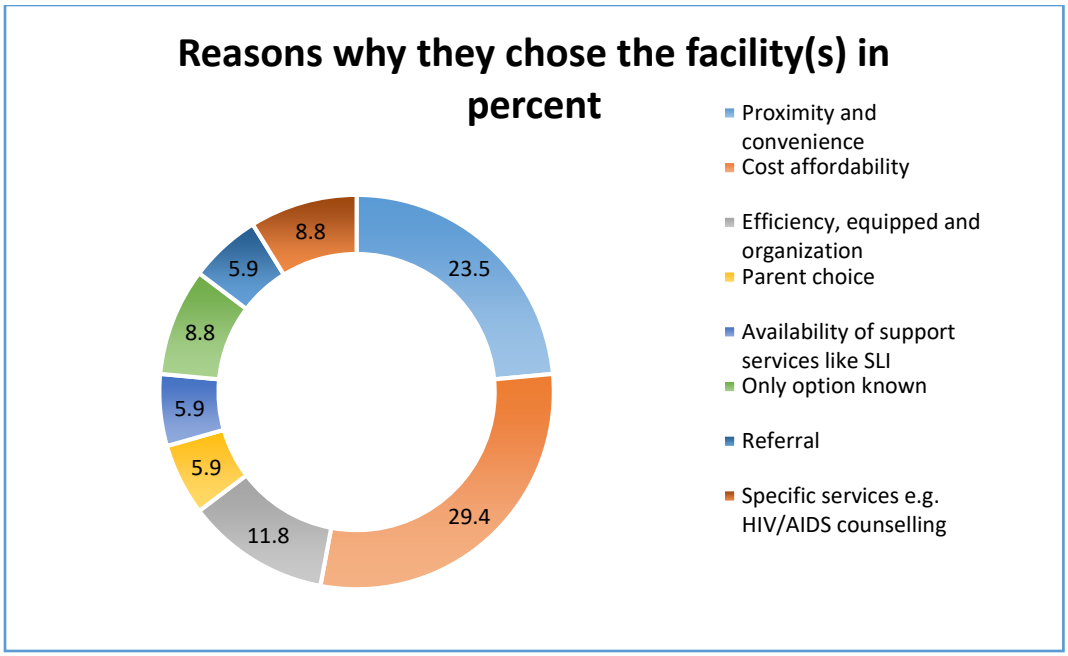

Figure 5: Summary of reasons for choice of facility to visit

Table 16: Cross tabulation of education, income, type of disability and type of facility

Education Level of respondents (Primary, Secondary and Tertiary)	**Average Income per respondent household**	
Type of disability of respondents	**Government**	**Private facility**
Primary level	438733.33	774600
Autism	-	360000
Epilepsy	91800	28800
Hearing Impaired		69600
Intellectual	36000	
Mental health	138133.3333	75000
Multiple	82800	168000
Visually Impaired	90000	73200
Secondary level	195000	120000
Cerebral Palsy	-	48000
Epileptic	-	0
Hearing Impaired	195000	72000
Mental health	0	
Tertiary level	216000	140000
Epileptic	-	0
Hearing Impaired	-	140000

Intellectual	180000	-
Visually Impaired	36000	-
No Education	100000	0
Multiple	-	-
Visually Impaired	100000	-
Grand Total	**949733**	**1034600**

The table above indicates income of respondents per type of disability, categorized per their education levels and the type of facilities they seek services from. Income levels can influence the type of facilities people can seek services from; and while education to some extent can influence income levels, there are other factors that determine type of facilities to visit like the insurance.

User friendly was assessed, as it could be a facilitator or barrier to access to services among persons with disabilities. Therefore, the respondents were asked if they found the facilities they visited as user-friendly; 75.5% found the facilities friendly as opposed to 24.5% who did not.

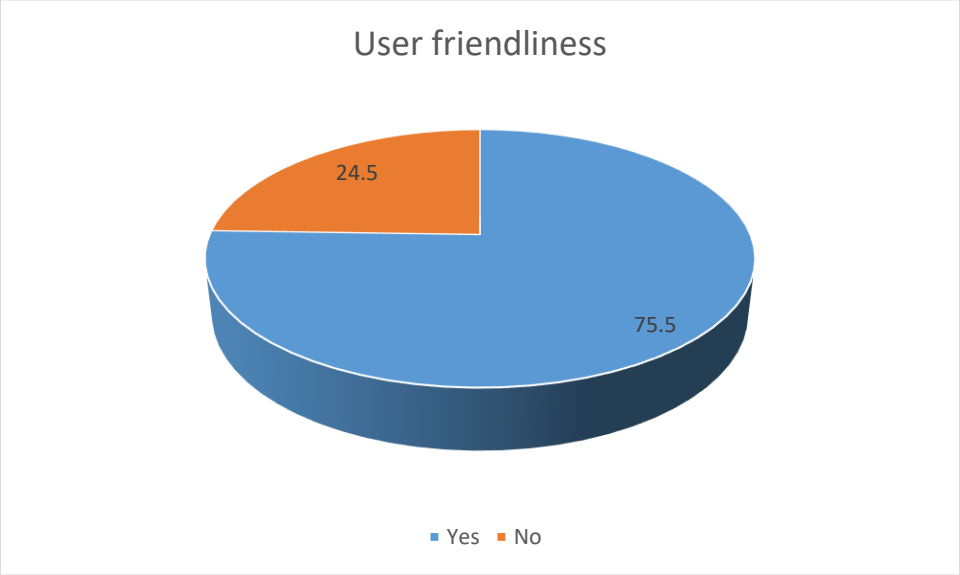

Figure 6: Respondents indicating facilities as user-friendly

Some of the reasons they gave for the “yes” included:

- Proximity
- Efficiency in the facilities
- In some, PWDs are prioritized
- At Dream Girl centre, there is a health worker with a hearing impairment and does assist those with hearing impairment
- In Lindi hospital, they have sign language interpretation services, making it easier for persons with hearing impairment

- At Kenyatta Hospital, they are very friendly especially for young people with disabilities who fear pregnancy related issues and they have a digitized system, that you can self-operate/respond.

Some of the reasons they gave for the “no” included:

- Communication barriers, in terms of accessibility and in the case where there is no sign language interpreter.
- In a private facility, it took too long to be served and yet it was an emergency
- They felt neglected
- There is failure when health workers cannot recognize disability
- The sign language interpreter brought to assist was poorly skilled
- “There are no experienced personnel to handle epileptic patients, they only gave her Panadol at Riruta Hospital, she was told to go for clinics yet she doesn't know when they happen”.
- They have a negative attitude towards disability
- There are no sighted guides

These findings reflect varied perceptions that inform PWDs to seek either services in a private or government facility and if they could opt for over the counter options. A number of issues with respect to their dignity has been raised, especially where the negative attitudes, and failure to recognize disability has been mentioned. PWDs deserve equal services like any other population, and their disability should not bring the difference, but should even be prioritized for services.

Section 3.5: Sexuality and Contraception

3.5.1: Sexuality

Sexuality and contraception are a key component of sexual and reproductive health for the population. The study wanted to find out the knowledge and capacity of respondents on sexuality and contraception; and their overall perception on accessing such services.

The study wanted to know on matters of sex, who the respondent felt more confident with to discuss such issues and why.

The respondents indicated various preference persons and their reasons, this included health workers and friends (n=9) respectively, parents (n=6), teachers and spouse (n=3). Some of their reasons included:

- Health workers and parents for privacy and confidentiality (n=3)
- Health workers give correct and accurate information (n=2)
- Closeness and free-will to share anything with the parent (n=2)
- Health workers are experienced and informed (n=2)
- Friends are trustworthy, and have time to listen (n=3)
- Husband know them better (n=1)
- Husbands hardly share information with others (n=2)

The data indicates that most respondents would prefer a doctor and a friend to share with issues of sexuality. For young and adolescents, the societal expectations on matters of sexuality are

hardly discussed, but the health care workers are open to such discussions and in most cases is the preferred go-to.

Discussions with spouse also reflect a better understanding of women needs and particularly women with disabilities. Marginalization often starts at the household level but embracing women at this stage indicates change of perception and attitudes in society.

Perceptions at the society on accessing sexuality information and sharing are influenced by religion, culture, education level and access to information. Persons with disabilities are far worse marginalized on accessing quality education, information and communication. Most often, they miss important information making them more vulnerable.

3.5.2: Contraception

Contraception or birth control helps one to avoid getting pregnant. The study wanted to understand if the respondents have ever received information on contraception. On information, 60.3% indicated yes, with 39.7% indicating no.

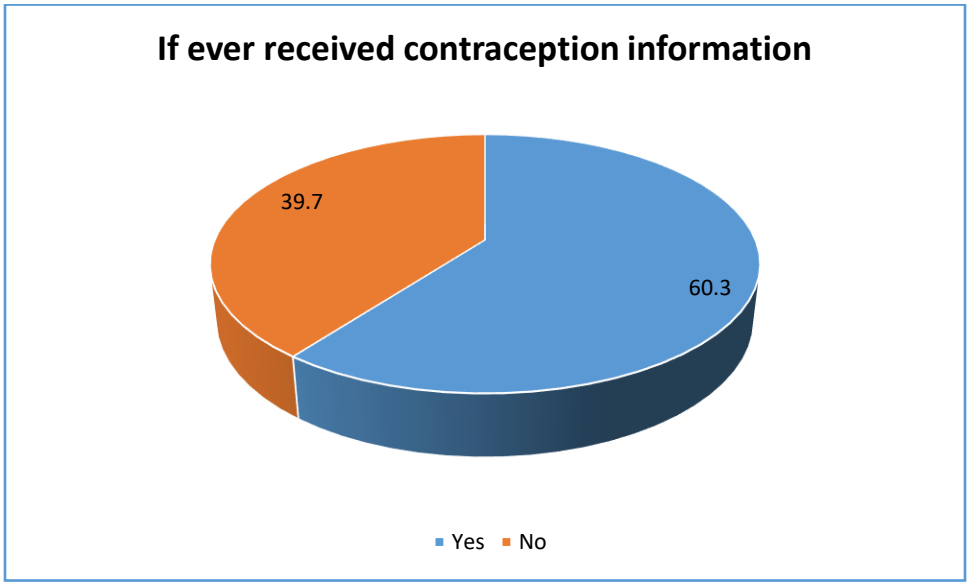

Figure 7: Access to contraception information among respondents

Most indicating they have received information (60.3%) were also asked if they felt their information shared was kept confidential between them and sources. 87.9% felt the shared information was kept confidential, as 12.1% indicated the shared information was not kept confidential. A key informant indicated that,

"*Sometimes you have to depend on the caregiver for information or communication, and therefore privacy is not there*"

"*Also, the challenge is some do not know how to write and this makes it a must you get a third party, which then compromises privacy*"

This is in line with the respondents who felt their privacy and confidentiality was not guaranteed. Particularly for persons with hearing impairment who may need a third party if the service provider

do not understand sign language. Respondents who felt their information was confidential were represented by 87.9% as those who did not were represented by 12.1%.

The study further inquired what sources of contraception information they received from. The health facilities leading at (52.4%), which also reflects the confidence they have in such institutions. Peers and facilitators followed at a distance with 7.1% respectively, media at 4.8% and multiple sources, church and community workers at 2.4% respectively.

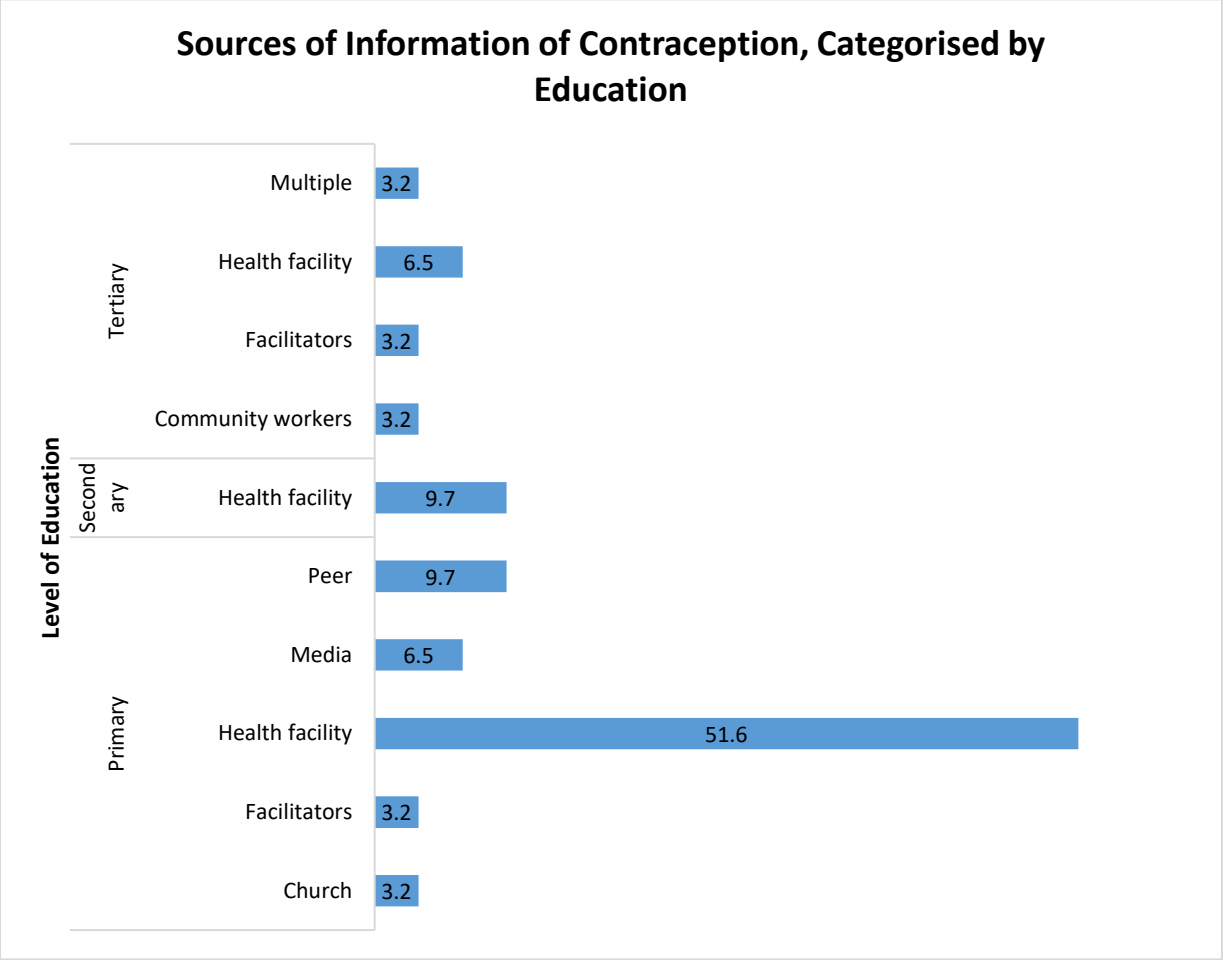

Figure 8: Source of contraception information, per disability type and education level

The figure 11 above shows different sources of contraception information categorized by education. Respondents with a primary level as highest qualification, health facilities at (65%) was the major source, followed by peer and media sources at 9.7% and 6.5% respectively. Others included facilitators and the church. The secondary level, health facilities were the only source reported at 9.7%. At tertiary level, health facilities were highest at 6.5%, followed by multiple, facilitators and community workers as sources. There is little significance on the different levels of education attained that can influence source of information on contraception; therefore, GCC should target all people regardless of their education levels.

Table 17: Tabulation of frequency of source of information per education level, disability type, location and sources

	Source of Information on contraception									
Level of education	**Primary**					**Secondary**	**Tertiary**			
Location	**Church**	**Facilitators**	**Health facility**	**Media**	**Peer**	**Health facility**	**Community workers**	**Facilitators**	**Health facility**	**Multiple sources**
Ayani			**1**							
Visually Impaired			1							
Bombolulu						**1**				
Cerebral Palsy						1				
Darajani			**1**							
Epileptic			1							
DC	**1**					**1**				
Hearing Impaired						1				
Multiple	1									
Forty Two			**2**	**1**					**1**	
Hearing Impaired									1	
Mental health			1							
Visually Impaired			1	1						
Gatwekera			**1**							
Visually Impaired			1							
Highrise			**1**							

Mental health			1							
Kabiria			**1**							
Epileptic			1							
Kambi-Muru						**1**				
Hearing Imapired						1				
Karanja			**1**							
Multiple			1							
Kianda			**1**	**1**			**1**		**1**	
Epileptic			1						1	
Intellectual				1						
Visually Impaired							1			
Laini Saba			**4**		**2**					
Epileptic			1							
Hearing Impaired			1							
Mental health			1							
Visually Impaired			1		2					
Lindi					**1**					**1**
Intellectual										1
Mental health					1					
Makina		**1**	**2**							
Epileptic		1								
Hearing Impaired			2							

Mashimoni			**1**					**1**		
Hearing Impaired			1					1		
Grand Total	**1**	**1**	**16**	**2**	**3**	**3**	**1**	**1**	**2**	**1**

The different media sources indicate reliability of these sources however varied, and with different channels. PWDs feel comfortable seeking services from the sources because of how they relate with the sources. The table shows little significance in terms of locality affecting sources of information. This is likely due to homogeneity of Kibera and the population that resides here. Most prefer health facilities, or rather is the known source for such information.

3.5.2.1: Contraception services

The study further wanted to identify if one has ever sought actual contraception services; and indeed 55% of the respondents have sought such services, and 45% have not. Based on the sources in the figure above, there is confidence that the services sought are reliable and minimal chances for asymmetry information exist.

A key informant highlighted that at Shofco facility, unplanned pregnancies are reported highly from the general population, and this could imply there is generally low uptake of contraception in Kibera, despite a good level of information that is accessible. In the focus group discussion, caregivers emphasized the need for awareness creation among persons with disabilities in the community, not much is shared with them at household level. Community forums held at different facilities to sensitize people on various health topics including sexual reproductive health, does not reach all, since majority are not able to get to the venue because of their status. They also said it is important for continuous health education at various facilities be targeted and done in a manner that all benefit, considering different impairment with their various accessibility needs.

3.5.2.2: Adequate services and Information

The study was also interested in identifying if the patients, who received services, were adequately responded to whenever they had inquiries. Among them, 86.2% indicated yes, 13.8% said no. The adequacy in responses points to conclusive understanding of the desired information for the service and the potential use of such information when need arises. This question intended to point out the quality of interaction between service provider; and the depth of conversations corresponding to the patient needs.

Table 18: Adequacy of conversations and responses:

	Frequency	Percent
Yes	25	86.2
No	4	13.8

The figure above indicates a good level of interaction with caregivers/PWD patients, on issues of their health. It also boosts confidence to PWDs to engage health providers even in the future on issues of their personal health.

Section 6: Human Immuno-Deficiency Virus/Acquired Immuno-Deficiency Syndrome (HIV/AIDS)

Sexual reproductive health encompasses a wide spectrum of issues including HIV/AIDS. This study sought to understand the knowledge level on the understanding of HIV/AIDS related issues among respondents. The respondents were generally asked if they have ever heard information on HIV/AIDS, if they had interacted with person(s) infected with the disease.

6.0: HIV/AIDS Awareness

The respondents indicated they are aware of the virus/disease at 100% but not all had interacted with persons infected. The study therefore set to inquire if they had sought HIV/AIDS services. Among them, 86.2% indicated they have sought the services, as 13.8% did not. HIV/AIDS perception is generally stigmatizing for the general population, and the persons with disabilities

would even be more marginalized. This influences the way they seek these services. A caregiver in the focus group discussion mentioned, the service providers treat them as if they have no right to receive the services. They are asked questions like,

"Ata wewe unafanyanga vitu kama hizo?" loosely translated as *"you also engage in such activities"*

Such discrimination experiences influence how PWDs seek services they much need.

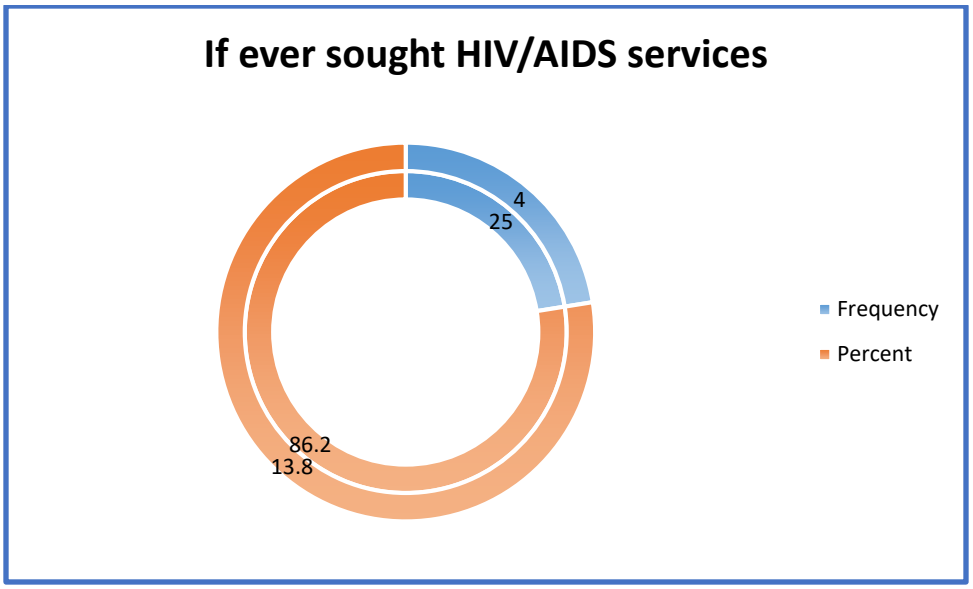

Figure 9: Respondents Seeking HIV/AIDS services

6.2.1: Quality of services offered

The study further sought to identify the quality of service provided on HIV/AIDS for those who sought such services. Among respondents, 35.1% felt the services were friendly, 27.9% felt they were satisfying and 25.2% confidential. However, 2.7% did not feel the services as friendly, 3.6 dissatisfying and 5.4% as non-confidential.

Table 19: Tabulation per option tested among respondents

	Frequency	Percent		Frequency	Percent		Frequency	Percent
Friendly	40	93	Satisfying	33	89	Confidential	29	83
Not friendly	3	7	Not satisfying	4	11	Not confidential	6	17

Respondents who indicated friendly (93%, n=40) and those who indicated confidential (83%, n=29) and those reporting satisfying (89%, n=33).

Figure 13 shows a summary of respondents who indicated friendly, satisfying and confidential or lack of particularly selecting to have observed all the dimensions.

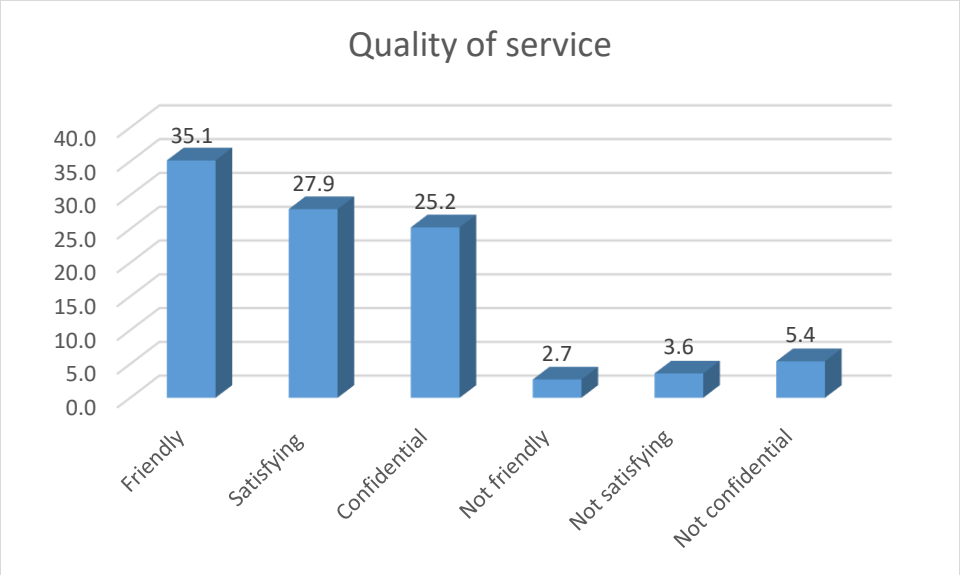

Figure 10: Quality of services offered as indicated by respondents

The study wanted to understand if respondents are living among persons who are infected and or affected and how they are living together. The respondents' responses on what is expected of them when living among HIV/AIDS infected or affected individuals in the communities. Their opinions on when someone has functional disability or not included;

- There is need to accommodate them in the community
- Advise them to adhere to medical prescriptions
- Be friendly, show respect care and love
- Encourage and empower them to live their full dignity
- Support them including daily needs
- Keep the information confidential
- Do not discriminate when offering assistance

Section 7: Maternal Health services

Maternal and newborn health is a critical component of sexual and reproductive health. The study sought to understand if respondents have ever sought any maternal health services. The response was 59.6 % yes, 40.4% no.

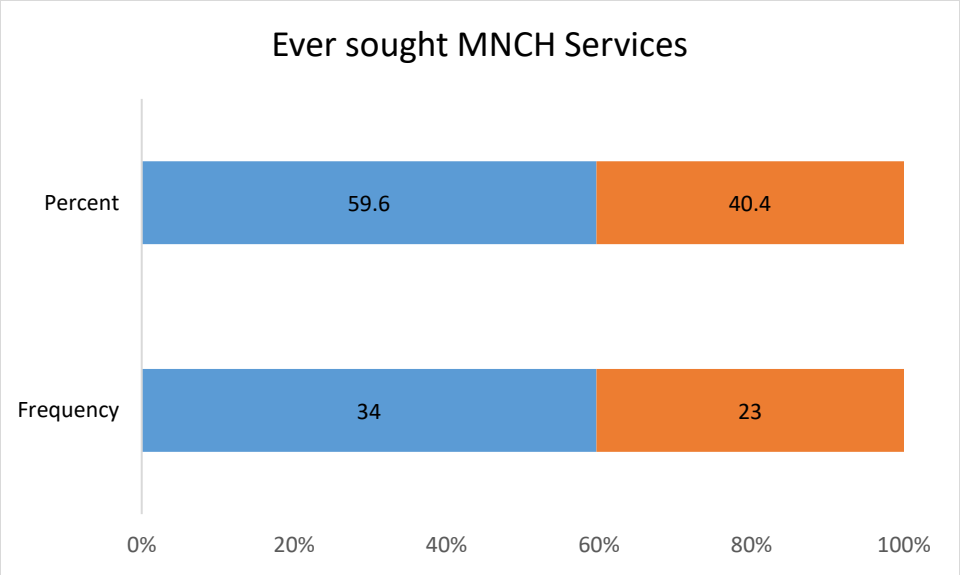

Figure 11: Graph indicates respondents seeking MNCH services

The study further wanted to identify which MNCH services are commonly sought. The responses indicated antenatal care at 41.3%, delivery at 31.3%, 25% for post-natal care and 25% for cervical cancer screening. This a good indication that the respondents are aware of key MNCH services provided.

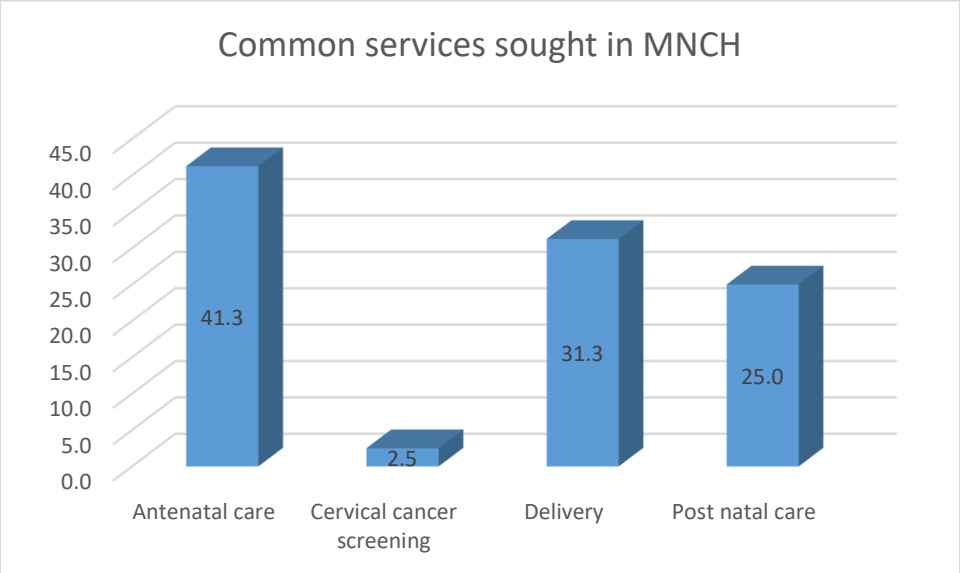

Figure 12: Common MNCH Services

The study further wanted to identify if the services offered at MNCH were satisfying to the desired quality. Majority (91.2%) felt the services were satisfactory, 8.8% felt it was not satisfying.

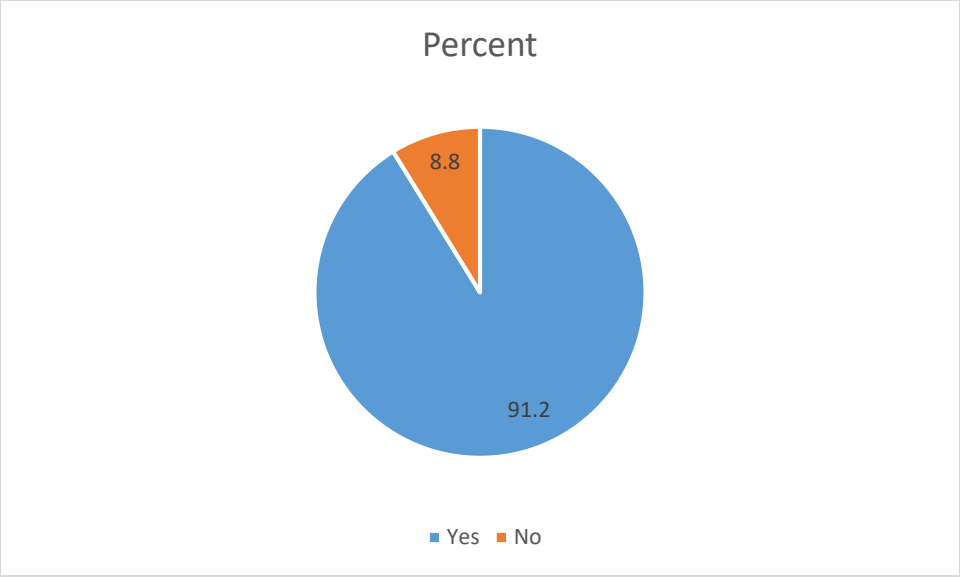

Figure 13: Satisfaction of service

4.0: Conclusion and Recommendation

Persons with invisible disabilities in Kibera have an opportunity especially in the sustainable development goal 3, on promoting health and well-being for all. The universal health coverage as a key area and part of the big four Agenda of the ruling party regime, will help build on the realization of their rights, access to services and demand for their rights/justice whenever infringed.

Opportunities for persons with disabilities, particularly women and girls exist in accessing sexual and reproductive health services, first as a compliance to the human rights laid in the Constitution and Persons with Disabilities Act. The second opportunity is through the development agenda of the government in promoting universal access to health; and lastly through the sustainable development goals (SDG 3), that aims to ensure all persons enjoy access to the right quality, affordable and appropriate services.

The study draws various conclusions in line with the objectives addressed.

4.1: Summary of findings

Bio data

All targeted participants were female. The average age was 31.24 years, averagely more youth than older person (35-49) years. Majority of respondents were single which also reflects on the household income.

With regard to education, majority had completed primary level, and transitionally, the numbers decreased. This indicates education advancement is limited among respondents, which exposes them particularly on the income levels and general knowledge and awareness on their rights.

Majority of respondents are employed (62%) and casual laborers at 24%. Self-employment and volunteers at 5% respectively and unemployed were 3.4%.

Most of respondents had a hearing impairment at 27.6%, followed by visual impairment at 19%, mental health at 17%, multiple disabilities at 13.8%, those with epilepsy at 12%, intellectual disability at 6.9%, cerebral palsy and autism at 1.7% respectively.

Majority of respondents' households were living above Kes. 190/= per day, the current basis for a person living below a poverty line at 66.7% and the others below the poverty line at 33.3%.

Knowledge and awareness on SRH

Majority of respondents are aware of SRH avenues to access information and services; this was reflected by well over 84%. In addition, they are aware of services provided by the facilities. The respondents highlighted different facilities they have visited seeking services in Kibera. Most popular as reported is Kibera South health center (government) and Shofco clinic (private) at 21.6% and 18.9% respectively.

As indicated by respondents, there is a likelihood to attend private facilities for services in comparison to government. Some of the facilitators could include distances to facilities, accessibility, affordability and acceptability. Government facilities could be sidelined as reported; there could be a tendency for health workers to ignore PWDs on queues, open discrimination,

long queues, distances and inaccessibility of the infrastructure, and expenses in terms of transport to and from.

SRH Information Access

Respondents they have received information on SRH at 73.7% and have visited facilities for such services at 63.8%. This shows majority have the necessary knowledge regarding SRH. However, there is still need to reach the others who reported not to have the information or visited a facility.

In terms of services offered, birth control was reported at 51%, followed by HIV/AIDS at 36% followed at a lower level with treatment, maternal health and relationships.

On source of SRH information, majority indicated health facilities as key sources (70.7%), schools, media and facilitators and parents were also reliable and common sources. Among facilitators, is Plan International and Action network for the Disabled who were highlighted as key in sharing relevant information. DPO units are important as they are often targeted to reach PWDs, and therefore, GCC should leverage on such to increase their reach. Therefore, GCC can leverage on the existing networks as they map other organizations working in the sector in Kibera.

Media was not recognized as among the top sources, and appreciative of the current infiltration of technology, mobile technology can link PWDs to more information regarding SRH. However, presumably economic status is a contributor to this state, and therefore social media did not feature much; however, there is appreciation of mainstream media including radio, TV and print.

The respondents indicated that health facilities are still top preference source of SRH information, as they reported health workers to be genuine and knowledgeable on the subject matter. Based on this trust, GCC can leverage to ensure health facilities are a key stakeholder in the service provision. Facilitators and media are also some good preferences, and these channels can be optimized to effectively provide the information and services.

The respondents indicated at 63.8% to have visited health facilities; and have sought contraception (52.8%), HIV/AIDS (23.3%), treatment and relationship counseling (3.3%) services respectively.

Persons with hearing and visual impairment (n=5) respectively sought contraception services, followed by mental health (n=4), then epilepsy and intellectual (n=2) respectively.

On HIV/AIDS, persons with hearing impairment (n=5) sought the service, followed by those with multiple disabilities and visual impairment (n=2).

On maternal health, those with hearing impairment and VI (n=2) respectively and epilepsy and multiple disabilities (n=1) sought the services respectively.

On epilepsy diagnosis and treatment, persons with epilepsy sought the service (n=1).

Service Accessibility

The respondents indicated they had sought the services and have found the services adequate (53.3%), affordable (51.7%), accessibility (55%) and on acceptability (51.7%). On average, the service provision has been found accessible. The accessibility was reflected upon admission of

service been informative and good, friendly and efficient (n=10); and services reported as affordable (n=9). The average indication was profiled by some facilities been expensive and lacking sign language interpretation services among other reasons.

Respondents indicated to have visited private facilities (54.2%) slightly higher than government facilities at (45.8%). Cost affordability, proximity and convenience was highlighted as key influencers; followed by efficiency, effectiveness, and specific services. Others include parental influence, availability of support services, and as only available option.

Sexuality and contraception

The respondents indicated they are free to discuss issues of sexuality with health workers and friends (n=9) respectively, parents (n=6), teachers and spouse (n=3). The main reasons been confidentiality, right information, experience, exposure and quality of information.

With regards to contraception, 60% indicated they had received information; and among them 87.9%, felt the shared information was kept confidential. Equally, respondents indicated that health facilities were the main sources of information (52.4%), peers and facilitators following at a distance (7%), media (4.8%) and others including multiple source, church and community workers.

Fifty-five percent (55%) received contraception services, the 45% measures need to be enhanced to promote the uptake with the right information.

On adequacy, 86.2% of respondents felt the services and information was adequate; this was interrogated further based on quality of patient-service provider interaction, and the depth of the interactions.

HIV/AIDS Awareness

All respondents are aware of HIV/AIDS. Among them 86.2% had sought services; however, a stigmatizing still exists particularly for persons with disabilities, as quoted, "*ata wewe unafanyanga vitu kama hizo?"* loosely translated as *"you also engage in such activities".* Such perspectives discourage PWDs from visiting facilities for such services.

Maternal health services

Fifty-nine percent (59%) of respondents had sought MNCH services. The common services sought in MNCH include antenatal care at 41%, delivery at 31%, postnatal care and cervical cancer screening at 25% respectively.

4.1.2: Summary of findings based on types of disabilities

The study identifies various challenges based on different types of disabilities.

a) Persons with hearing impairment

The Hearing Impaired who were the majority sampled in the study, expressed group specific challenges they face at community and facility level. Key was communication barriers particularly where few people have sign language skills.

At the community, they are misunderstood making them less interactive with other members of society; and therefore it is difficult for them to express their feelings or challenges they are experiencing. At facilities, health workers attending to their needs do not understand sign language, which makes it quite difficult for confidentiality. This has made it quite difficult for HI to freely express themselves, as their translator/interpreter is preview of the personal discussions.

HI calls on the government to train health workers on sign language, who can then be direct contact and interpreters so that their health issues are kept confidential and within health facilities. This will also enhance their health seeking behaviors and overall improve their health.

b) Persons with visual impairment

They have specific challenges that are categorized as communication and infrastructural barriers. They indicated that communication barrier is the largest hindrance, the channels of information sharing particularly and the sources are limited because of the braille. Often, information is transmitted verbally and they benefit for instance in continuous health education that occurs in health facilities.

They recommend that the government and health facilities consider their plight especially in production of information. They recommend for inclusion in programming of health interventions, as well on how to reach them.

c) Person with intellectual and mental health conditions

This group feels they are not understood; they are discriminated in communities largely and they hardly associate with other members of the community besides their immediate families. In health facilities, they have regular doctors whom they find it easier to interact with. There is a large dependency on caregivers, which limits confidentiality between service providers and themselves. They feel the community need to understand them and support them. There is need for awareness creation in communities.

d) Persons with multiple disabilities, epilepsy and autism

These groups of people continue to face challenges at community level and service provision points. The discrimination is worse at community level as they are not understood including at family level. Only caregivers assist them. There is need for communities to be empowered regarding these kinds of disabilities so they can learn how to cope and support such persons.

Despite the existence of opportunities, challenges exist at different levels, this study identifies two critical levels; first is the institutions mandated to protect the interests of persons with disabilities. Deliberate efforts must be made to ensure such institutions advocate for mainstreaming of services within other institutions.

The second level is to address the negative attitudes and norms of the society; persons with disabilities continue to be discriminated against many privileges and rights. As a measure to ensure PWDs enjoy their rights and privileges within their immediate communities; is to enhance their participation in community activities, by mainstreaming services across different aspects of life (economic and social).

4.1.3: Cross cutting considerations

The study also noted key challenges across the service providers and communities:

Service providers in different facilities acknowledged the various needs that persons with disabilities face while seeking services. Amidst, various commitments at County and National levels of government reflected in the County Integrated Development Plan and the Medium term plan III respectively; there is still a big gap to be pursued. These efforts ought to be targeted towards individual attitudes, standard operating processes to be mainstreamed in government and private facilities that cater for all people including interests of PWDs.

The study findings point toward effective project implementation in terms of intervention, and the most impacting pathways (stakeholders). Nevertheless, it helps the project where there needs to be a strengthened focus and who can enhance their success. Disability as a focus area needs to be understood at individual, institutional and policy level, therefore partnerships is a sure collaboration way to enhance sustainability.

The study draws various recommendation in light of the context to key players to be involved to the success of this project.

4.2 Recommendations to Gifted Community Centre per Sector Area

a) SRH services accessibility

The knowledge and capacity levels among respondents was above average, however, the education levels are low to average; making it very necessary for GCC to infuse training and awareness creation in their interventions. The awareness creation should aim at creating knowledge base and utilize community health workers to enhance practice of the awareness. The accessibility is good, however, a mainstreamed approach will favor women and girls with disabilities where service providers are fully aware and recognize the need to provide the much needed support and services to persons with disabilities.

b) Sexuality and Contraception

There is general good knowledge on contraception, however, the uptake is not optimized, this could be because of other factors like religion, culture and economic status. This can be strengthened by collaborating with different NGOs, private and government institutions to provide conducive avenues like youth café, and clinics especially for youth. Mainstreaming of the services that includes enhancing better services for PWDs and inclusive approaches of communications and adapted materials for information in different formats. Enhance confidentiality and privacy through introducing mainstreamed service provider like sign language interpreters. GCC to optimize existing avenues to ensure the target group acquire the right information.

c) HIV/AIDS

There is good level of knowledge on HIV/AIDS, its manifestation and how to treat infected persons. The gap exists at the service provision point; the respondents indicated the discrimination that they face when seeking these services. It is important that GCC engage health facilities and any other facilitating agency on HIV/AIDS to be a key partner for effective

implementation. GCC should develop a comprehensive in and out of school based sexual education on HIV/AIDS, and STIs.

d) Maternal and Child Health

A number of services including antenatal care, postnatal care, deliveries and cervical cancer screening have been sought. The level of knowledge can be enhanced among PWDs but strong focus should target service providers to help them mainstream their processes to target PWDs. Target traditional birth attendants to encourage women with disabilities to seek assistance from health facilities.

Recommendations to Disabled People Organizations

As units where PWDs are organized, with quite a number of DPOs in Kibera, they can engage service providers and partner organizations to advocate for their rights in health and other social needs. It is therefore, prudent that this project engages DPOs at the outset to ensure their participation is systematic, and because of their membership reach, more PWDs shall benefit including those with visible disabilities. DPOs can enhance their awareness creation activities that will educate communities on issues of persons with different types of disabilities.

Recommendation to National Council of Persons with Disability

As a mandated unit by the government to protect the interests of persons with disabilities, GCC can engage their participation and involvement to ensure they provide the necessary services for PWDs; that will further empower them to demand for their rights. Most PWDs especially youth ones do not have PWD identification cards, which can limit their enjoyment of rights that comes with the card.

Recommendation to Partners/Nongovernmental organizations

NGOs working on SRH and rights ought to target PWDs as well; respondents mentioned Action Network for the Disabled and Plan International as organizations that provide facilitation to SRH information in select forums. There is need to increase such interventions and ensure they are inclusive of PWDs, so they can benefit. As a result, GCC should conduct a SWOT mapping to understand which player is important to engage with based on what they are doing and their approaches. This will be important for partnership and collaboration going forward.

APPENDICES 1

A1: Study Tools (Questionnaire, Key Informant Interviews, Focus Group Discussion Guide)


Focus Group Discussion Caregive


Key Informant_Interview


Questionnaire WomanGirl 15_49.d

A2: Assent Form

Gifted Community Centre- GCC is a registered, independent, disability and development youth led (community-based) organization formed for and by youth with disabilities in Nairobi, Kenya. It was formed by two youth with disabilities who share a vision of an empowered and inclusive society. We majorly target youth/persons with disabilities residing within the informal settlements of Nairobi, especially Kibera, and college/university youth with disabilities. We MENTOR, EDUCATE, INFORM, EMPOWER, and ADVOCATE on and for the Rights of Persons with Disabilities in pursuit of independence, decent living, and full utilization of untapped potential of youth with disabilities.

Gifted Community Center is conducting a baseline survey for a project dubbed ***'silent conversations: Enhancing HIV and SRH knowledge for Women with Disabilities***' which is envisaged to create an enabling environment for access and the right to comprehensive SRH and family planning services.

You have been selected through a random selection process to take part in a baseline survey that is expected to provide information about the different SRHR needs, capacities and coping strategies of women and girls among the communities in Kibera. You will take part in either a 2-hour focus group discussion; fill in a self-administered questionnaire, or Key Informant Interview or either two.

Sexual reproductive health and rights includes maternal health, sexuality, and family planning and HIV/AIDS issues. All information collected will be kept confidential and will be used for the purpose of this assessment only. Your identities will be concealed.

By writing your name and/or signing below, you are assenting to participate in the Gifted Community Centre SRHR baseline activities under the conditions described above. You may revoke this permission at any time. If at any time during the program you have questions, feel free to contact your facilitator or GCC.

_____

_____

Name of Participant Signature or Thumbprint

A3: Consent Form

Gifted Community Centre- GCC is a registered, independent, disability and development youth led (community-based) organization formed for and by youth with disabilities in Nairobi, Kenya. It

was formed by two youth with disabilities who share a vision of an empowered and inclusive society. We majorly target youth/persons with disabilities residing within the informal settlements of Nairobi, especially Kibera, and college/university youth with disabilities. We MENTOR, EDUCATE, INFORM, EMPOWER, and ADVOCATE on and for the Rights of Persons with Disabilities in pursuit of independence, decent living, and full utilization of untapped potential of youth with disabilities.

Gifted Community Center is conducting a baseline for a Project dubbed ***'silent conversations: Enhancing HIV and SRH knowledge for Women with Disabilities***' which is envisaged to create an enabling environment for access and the right to comprehensive SRH and family planning services.

You have been selected to take part in a baseline survey that is expected to provide information about the different SRHR needs, capacities and coping strategies of women and girls among the communities in Kibera.

Sexual reproductive health and rights includes maternal health, sexuality, and family planning and HIV/AIDS issues.

You will take part in a 2-hour FGD with other 8-12 participants who are caregivers that might also be recorded. All information collected will be kept confidential and will be used for the purpose of this assessment only. Your identities will be concealed.

By writing your name and/or signing below, you are consenting to participate in the GCC baseline activities under the conditions described above. You may revoke this permission at any time. If at any time during the baseline you have questions, feel free to contact your facilitator or GCC.

_____ _____

Participant Signature or Thumbprint Facilitators' signature

Date

A4: Video/Photo Consent Form

Video and Photo Consent and Release Form

Gifted Community Centre produces a variety of different materials to communicate and inform people, charitable trusts, organizations and relevant stakeholders about the work that we do. Occasionally, these materials will include photos, videos, voice record, and environment of surroundings, parents and guardians. The materials are to share the work we do and the achievements we make.

Without expectation of compensation or other remuneration, now or in the future, I hereby give my consent Gifted Community Centre, its affiliates and agents, to use my image and likeness and/or any interview statements from me in its publications, advertising or other media activities (including the Internet).

This consent includes, but is not limited to: (Initial where applicable)

(a) Permission to interview, film, photograph, tape, or otherwise make a video reproduction of me and/or record my voice

(b) Permission to use my name and

(c) Permission to use quotes from the interview(s) (or excerpts of such quotes), the film, photograph(s), tape(s) or reproduction(s) of me, and/or recording of my voice, in part or in whole, in its publications, in newspapers, magazines and other print media, on television, radio and electronic media (including the Internet), in theatrical media and/or in mailings for educational and awareness.
This consent is given in perpetuity, and does not require prior approval by me.

Name: _____

Signature: _____

Address: _____

Date: _____

The below signed parent or legal guardian of the above-named minor child hereby consents to and gives permission to the above on behalf of such minor child.

Signature of Parent

On the other hand, Legal Guardian: _____ Print Name: _____

The following is required if the consent form has to be read to the parent/legal guardian:

I certify that I have read this consent form in full to the parent/legal guardian whose signature appears above.

_____ _____

Date **Signature** of Organizational Representative or Community Leader

A5: Photo
Upon request

Consultants:

Harsley Wesisi

Malkia Abuga

Gifted Community Project Team

Sarah Musau, Programs Director

Mary Kamwende, Project Coordinator

Agnes Wacuka, Finance Officer

Jeremy Murithi, Director